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TITLE: CITIZEN CONSULTATION
SUBTITLE: Citizens Meeting Preparatory Materials

ASSET Project • Grant Agreement N°612236

ASSET

Action plan on SiS related issues in Epidemics and Total Pandemics

7th RTD framework programme

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TRAINING MATERIAL FOR PROJECT MANAGERS ON EXECUTION OF THE CITIZEN MEETINGS



MANUAL FOR ASSET - MOBILISATION AND MUTUAL LEARNING ACTION PLAN

Part 1: Overview

About the manual

The purpose of the manual is 1) to set the scene for the question of pandemics and how to deal with them in terms of governance, public communication and inclusion; and 2) to outline everything that needs to be done before, during, and after the specific citizen consultation process that will take place as part of the EU project ASSET, WP4 (for an introduction to the ASSET project, cf. Part 2 of this report).

In outlining ways to deal with pandemics, generally, the manual aspires to suggest a framework for identifying and deciding on the most appropriate approach to risk communication and governance vis-à-vis pandemics: How to communicate? How to include the wider public? How to decide on an action plan for warning levels, vaccine programs etc. – these questions have different answers, depending on the kind of pandemic threat and the least the stage: prior to, during or post-crisis.

We suggest a framework to analyze these different situations and outline a variety of methods that apply well to each situation.

The manual is, however, first and foremost a guide for ASSET project managers and staff (including group facilitators) responsible for organizing and carrying out the citizen consultations in September 2016.

Since culture, traditions, and resources differ from country to country and from partner to partner you may find that there are some things you will have to do differently in your country. If you have to do things in a different way than described in the manual you must check with DBT whether that can be allowed. To secure a uniform and transparent process the following points must be followed completely:

- The group of selected citizens has to be varied in relation to age, gender, geographical zone (city and countryside), educational level, ethnic affiliation, occupation.
- The citizens must be lay people, and thus not affiliated with any type of health organization
- The structure of the citizen consultation program must be followed, and it may not be shortened.
- Deliberations and voting should be carried out as described.
- The questions and the information material may not be changed.

Citizen Participation and ASSET

An elaborate section explaining the reasoning behind citizen participation in the ASSET project will follow in the ASSET Policy Report.

Part 2: ASSET Citizen Consultations

Project objective

ASSET (Action plan on Science in Society related issues in Epidemics and Total pandemics) is a 48-month Mobilization and Mutual Learning Action Plan (MMLAP), co-funded by the European Commission. ASSET comprises an international group of experts in public health, social and political sciences, vaccine and epidemiological research, science communication and media. Overall, the ASSET project aims to address a wide array of issues around major infectious disease outbreaks toward the creation and elaboration of a consolidated action plan, which comprises the following steps/objectives:

1. To forge a transdisciplinary partnership to effectively address epidemics and pandemics.
2. To explore and map science in society related issues in epidemics and pandemics.
3. To define and test a participatory and inclusive strategy for successful action¹.
4. To identify resources necessary to make the action sustainable after project completion.

Each of the abovementioned steps/objectives manifests a critical phase in the life-cycle of the ASSET project. The present manual links directly and contributes to the accomplishment of the citizens meeting preparatory materials of ASSET, within the wider scope of Work Package 4 (WP4: Citizen Consultation), the WP4 will carry out a public consultation. Its main objectives are to:

1. Make a concrete and policy-relevant example on EU level coordinated public consultation with a link to parliaments;
2. Give input to policy-making about policies on pandemic crises, in terms of expression of informed ideas and opinion from near-representative samples of citizens;
3. Engage citizens in the debate of pandemic crisis prevention and management.

This present manual constitutes a key component of this exercise, as it describes the rationale for and method of public participation within the ASSET project. It builds on the contents of the ASSET Action Plan Handbook and ASSET Tool Box (WP3).

¹ As a Mobilization and Mutual Learning Action Plan, ASSET will test participatory methods for how to include citizens in pandemic governance.

Following the national citizen consultations, which are to be organized in eight countries across Europe coordinated by the Danish Board of Technology Foundation, national partners will disseminate policy recommendations to their national stakeholder, including but not limited to, national parliamentary committees, industry and civil society organizations. The Danish Board of Technology Foundation will organize a Policy Workshop at the European Parliament (m36), at which the results of the project are communicated to MEP's of relevant committees. The Policy Workshop will be carefully aligned to WP6, Policy Watch.

Citizen Recruitment

The very objective of the ASSET project is to introduce the informed opinions of citizens from all over Europe to European decision-makers and future political discussions about pandemics and epidemics. The comparability and credibility of the project are entirely contingent on credible citizen recruitment. It is therefore necessary, that you follow the guidelines in the recruitment of the citizens and that the citizens collectively reflect the demographic diversity of their country. Please be aware that it is often underestimated how much time it takes to plan and implement good citizen recruitment.

The selection of citizens

In order to make results comparable and trustworthy in the eyes of the media and politicians it is important that participating citizens in the project are selected according to the same set of criteria in all countries. Citizens participating in the project should therefore reflect the demographic distribution of the general population in your country with regard to the following parameters:

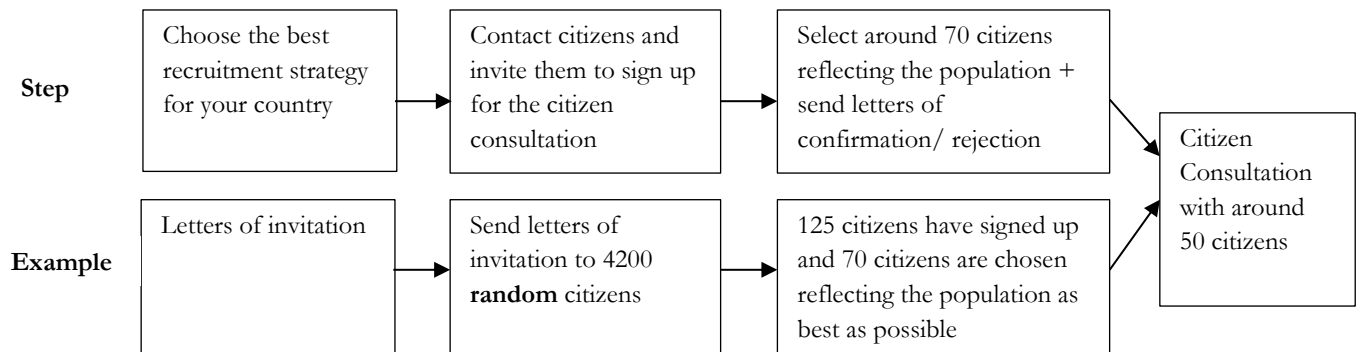
- Age (from 18 and up)
- Gender
- Geographical zone (city and countryside, specific region)
- Educational level
- Occupation (employed, unemployed, public sector, private sector, student, retired, etc.)
- Other criteria of national relevance

It is also important that all participating citizens are lay people, meaning that they should not be people working professionally with health care – e.g. scientists researching epidemics or professional health care workers dealing with cannot be considered lay people. Neither can politicians or officials working for the government with public health. Apart from that, the line between professionals and lay people can be difficult to draw in practice, but it is important to pay attention to it, since professionals would potentially be

too dominant in the deliberations, where citizens' attitudes, concerns, and opinions (not just hard facts) are to be debated.

To avoid crossing this line you should avoid recruiting citizens via organizations with vested interests in public health.

Figure 1: The different steps in the recruitment process and an example



In order to make sure that you will get a varied group of citizens according to the parameters mentioned above you will need to get around 125 citizens to sign up for the citizen consultation. This means that you need to contact even more citizens to have about 125 citizens to sign up – in Denmark we usually send out letters to more than 4200 random citizens in order to make 125 citizens sign up. When they have signed up you will choose at least 70 citizens, which as a group match your country's statistic on the parameters, and you send them letters of confirmation (this is taking into account that some will not show up on the day). You will then have to send polite letters of rejection to the rest.

Please note that *not* all citizens who have received letters of confirmation will show up at the citizen consultation. This can be due to sudden illness, loss of interest, etc. In order to make sure that at least 50 citizens show up at the citizen consultation you should send out letters of confirmation more than 50 citizens. In Denmark our experience is that you need to confirm 20 citizens extra in order to reach the 50 citizens needed. Depending on the culture of your country or if the citizen consultation is during the weekend or a national holiday you might need to confirm even more than 70 citizens. You will be the judge of how to proceed in your country and estimate how many extra citizens you need to confirm in order to reach a number of 50 citizens on the citizen consultation day. You could also make a follow-up call to remind participants one week before the citizen consultation. This is up to you.

Any claims to “statistical representativeness” should be avoided. A group of 50 citizens, however, is big enough an amount to give a realistic picture of the quantitative tendencies. And *if* the 50 people chosen in each country reflect the composition of the population according to the parameters listed above, the results will give a credible snap shot of the views of the population in your country or region in general.

How to recruit the citizens

Citizens can be recruited in a number of different ways. The recruitment of citizens should begin at least two months before the citizen consultations, depending on your recruitment process. Due to summer holidays we recommend you start the actual recruitment no later than the beginning of June (see timeline). There are a range of different methods to recruit citizens. As long as the criteria described above are followed, the following methods can be used:

- **Sending letters of invitation.** Addresses may be obtained from a national (or regional) central office of civil registration. The office can draw out a large representative set of civil registration numbers and addresses according to the parameters mentioned above. It is very important to ensure that the addresses are **random** since this is the key in order to get as close to a representative sample as possible. Furthermore, it is important to pay attention to the fact that only a small part of the invited citizens will actually agree to participate in the end. In Denmark typically 2.5-3% of invited citizens sign up for the citizen consultation. In order to get 125 citizens to sign up we need to send letters to around 4200 citizens. These numbers might differ from country to country, but the point is that you must expect that only a few of the invited citizens will actually sign up for the consultation.
- **Buying addresses from a market research company.** A sample of addresses that reflects the national distribution on as many of the listed parameters as possible can be bought i.e. from a market research company. The rest of the procedure is described above.
- **Recruitment by telephone.** If it is neither possible to get a random sample of addresses from the civil registration or a market research company, you could also contact citizens by telephone, if a national telephone register is available. In order to get a good sample, you should think carefully about which phone numbers you pick. An efficient solution is to pick numbers randomly - you could for instance pick 50 random pages in the phone book and then call 50 random citizens on each page (you will then call the citizens until you have around 125 citizens that have signed up). Before calling them you should have thought out a



good “speech” that will make them interested and you should also think through what will happen if they say yes, should they register on a webpage? What about citizens without net access? Finally it should be noticed that this approach is very time consuming. Do you have the staff for this exercise such as (cheap) student assistants? If this is not the case it might be cheaper to get a private company to do the job.

- **Face-to-face recruitment based on quotas in geographical clusters.** Another way of inviting citizens is via face-to-face recruitment. If you choose this method you should again think very careful about how you execute the recruitment process. It is very important that you ensure diversity in your sample so that the participants in the end reflect the population as well as possible. An example could be that you select 30 different recruitment areas around your country – you could for instance pick 5 different geographical regions and within each region you pick 2 random schools, 2 random hospitals, and 2 random shopping malls. At each setting you aim at getting as many as possible to sign up for the citizen consultation (filling out an enrolment form, see Example of Letter of Invitation, page 33).

Instead of aiming at maximising the amount of citizens signing up for the consultation you could also aim more specifically for different “types”. You could for instance make different profiles of whom to invite, with different ‘values’ on the parameters above. This could be coordinated and calculated in advance, so that when you do the recruitment in each geographical area you would know that you are looking for e.g. a male in his 50’s with low educational level, an elderly female with middle education and working in the public sector, a female student etc. Again, in order to get the right distribution of citizens (to ensure a variety of citizens) you will need to get around 125 citizens to sign up for the citizen consultation.

Just as the telephone strategy this one is also very time consuming. Do you have the staff for this exercise such as (cheap) student assistant? If this is not the case it might be cheaper to get a private company to do the job.

- **Snowball-sampling.** This recruitment procedure could be used in a geographical area where you do not know how to get in touch with the target group citizens needed for the citizen consultation. You invite three persons and ask each of them to make three copies of the invitation letter and give them to three people they know, who will then do the same (make three copies, etc.). In this way the sample group appears to grow like a rolling snowball. The snowball strategy has the disadvantage that citizens might primarily invite people similar to themselves, so you need to emphasize that they should invite people with different backgrounds/characteristics compared to themselves.

- **Advertising.** Advertising in different media (newspapers, radio, etc.) is another way of recruiting. Citizens would be encouraged to send their applications to the national partner and selection could be made as described above according to the demographic parameters. If choosing this recruitment strategy, please pay special attention to the fact that you reach different target groups, by advertising in different kinds of media and media that cover different groups in the population.

The most important thing to have in mind when choosing your recruitment strategy is to make sure that citizens selected reflect the national distribution of citizens according to the parameters. In order to achieve this, more than one of the recruitment methods described above may have to be used. If it is difficult to reach a group of participants that reflects the populations in your country/region, it might be a good idea to supplement a random selection strategy with a targeted recruitment towards those groups that are underrepresented in the group of citizens that have signed up. It could be because there is a large overrepresentation of a certain type of citizens, e.g. an overrepresentation of males, old people or well-educated people. Hence the targeted selection could be aimed at women, young people, less-educated people, minority and ethnic groups.

Per Diem

In some countries it is customary that citizens are paid a set fee for attending citizen participation activities, and therefore also events such as this citizen consultation. If the citizens are paid a fee, it is vital that the amount is well balanced in order to avoid that money is the only motivation for participating, and it should also be made clear to the citizens that they are not paid to have a specific opinion or to answer the questions in a certain way. It is important that no one can claim that the results have been influenced by paying the citizens to participate.

Timeframe

As mentioned above, the actual recruitment process should start at least two months prior to the citizen consultation on September 24th 2016. Reminders should be sent to the selected citizens 1-2 weeks before September 24th. All partners should prepare a national citizen recruitment strategy in March and send this first draft to The Danish Board of Technology no later than March 15th. Thus, it is possible to discuss the recruitment strategies at the training workshop March 21-22th. After the training workshop all partners can make the necessary adjustment on their strategies and send their final recruitment strategy to DBT before April 4th. A strategy form is attached under 'Templates and Scripts', page 29. This form looks similar to the one you should send to DBT before March 15th.

Focus: letters to citizens in the recruitment process

Letter of invitation

A letter of invitation is to be sent or given to every potential participating citizen. The letter should be short and encouraging and should include the following:

- Introduction of the project
- Explanation of the basic citizen consultation details (when and where), that it is not necessary to know anything about the subject in advance and a note that the letter of invitation does not grant permission to the citizen consultation in itself. Their participation needs to be confirmed.
- An application form, which should be easy to fill out. It should ask for information about applicant's age, gender, geographical zone of residence, education, occupation, and other criteria of national relevance (if relevant). It should also ask for special needs concerning catering (allergies, vegetarian, vegan, kosher, etc.).
- An addressed (and maybe stamped) envelope so that the application form can be returned, or an internet address/email/phone number of where to sign up.

A template illustrating how a letter of invitation could be formulated is presented in 'Templates and Scripts', page 33.

Letter of confirmation

After having selected around 70 citizens according to the demographic parameters, you must send out a letter of confirmation to the selected citizens. The letter of confirmation is the admission ticket to the citizen consultation.

The letter of confirmation should contain the following documents:

- Onepager about ASSET
- Information booklet about ASSET
- Practical information
 - Time and place
 - Transportation (how to get there)
 - Accommodation (if needed in your country)
- Contact information (if someone wants to reach you)
- An appeal to the citizens to inform you if they are not able to attend the citizen consultation

For citizens to take part in the discussions at the citizen consultations they should be encouraged to read the information booklet carefully. If experience tells you that citizens cannot or will not read the information booklet, you will have to use other methods to communicate the information on epidemics and pandemics that is contained in the information material. One approach could be community briefings, in the days prior to the citizen consultation, at which citizens are informed and educated - or maybe even better - to make a webcast where the information booklet is read out loud. You can also

invite citizens to come the day before and go through the information material, but you should **NOT** start the discussion before the citizen consultation on September 24th 2015.

A template is presented in 'Templates and Scripts', page 38.

Letter to non-selected citizens

When you have selected citizens to whom you will send the confirmation letter (according to the parameters described above) you must send a polite letter of “rejection” to those who have signed up for the citizen consultation but who have been screened out. Remember to thank non-selected citizens for their interest and their enrolment, and explain that they have not been selected in order to get a group of participants that reflects the socio-demographics of the general population in your country.

A template is presented in 'Templates and Scripts', page 39.

Letter templates

If you use the templates you have to translate the letters to your local language. The structure of the templates should make it easy to use without any big changes - just translate the letter and add the information specific for you in sections like *<these>*.

The Venue

Facilities

The venue (the place/room where the citizen consultation is going to take place) should have the following facilities:

- Big plenary room with space enough for staff and 60 people seated at round tables (approx. 200-300 square metres).
- 10 round tables hosting 7 citizens and a group facilitator (round tables make the dialogues more intimate, inclusive etc. and are therefore important).
- A stage from where the head facilitator can speak (should be visible to everybody).
- Comfortable chairs. Hard plastic chairs might become painful after several hours to some participants. Remember that some participants might be elderly and some might be physically disabled. Therefore padded chairs should be considered and check accessibility for wheelchairs.
- Wardrobe facilities. Preferably burglary secured such as lockers, or staffed cloakroom.
- A buffet from where the citizens can take their drinks and food.
- A smaller extra room for technicians and gear (copying machines, printers, storage space).
- Toilets
- A designated area for press and other visitors.
- Outdoor facilities if someone needs fresh air or to smoke.

Technical equipment:

- At least three computers with Internet access – VERY IMPORTANT. The computers should have a Windows or Windows compatible operating system.
- Microphone and loudspeaker system.
- Big screen or monitor visible to all participants.
- Projector (compatible with the computer).
- Good sources of light that can be dimmed during video presentations.
- Video recorder for interviews and a camera for documenting the citizen consultation.
- Printer and copying machine.
- A webcam thus you can connect with other citizen consultations during the day.

It is very important that no one can question the credibility of the results from your citizen consultation. Therefore, it is not allowed to show posters or other forms of exhibitions at the venue that send any particular message to or try to influence the opinion of the citizens (for example posters urging citizens to change their lifestyles towards national health advice or campaigns for local/national health action).

Seating plan

At each table the citizens must be mixed according to the criteria for the citizen recruitment. This means that at each table the citizens must be mixed in regard to age, gender, education level etc. This also means that e.g. citizens from the same village cannot be seated at the same table. Before the citizen consultation you must therefore make a seating plan that mixes participants as much as possible. This gives the citizens an opportunity to talk to people from other parts of the country and with different backgrounds than their own, and by mixing them there is a good chance that the deliberation will reflect different experiences and points of view. Thus we will ensure that the citizens have reflected on other points of view before casting their vote.

We recommend that you have fixed seating for the entire day. This will create a strong group dynamic at each table. People will become more confident and comfortable. They will be able to discuss throughout the day and will not have to start the discussion from zero at each session. At the same time, you will have a risk that some strong-minded participants will overrule all other participants at one table during the whole day. This would mean that some citizens will not really be able to speak freely. It is the task of the table facilitator to prevent this from happening. It may be, though, that the table facilitator will need assistance from the lead facilitator in order to remind the citizen in mind about the rules for good dialogue.

Minority groups

The spirit of the project is that the citizens get mixed in order to engage in a dialogue with people from different backgrounds, ages, gender etc. than themselves. However, if you



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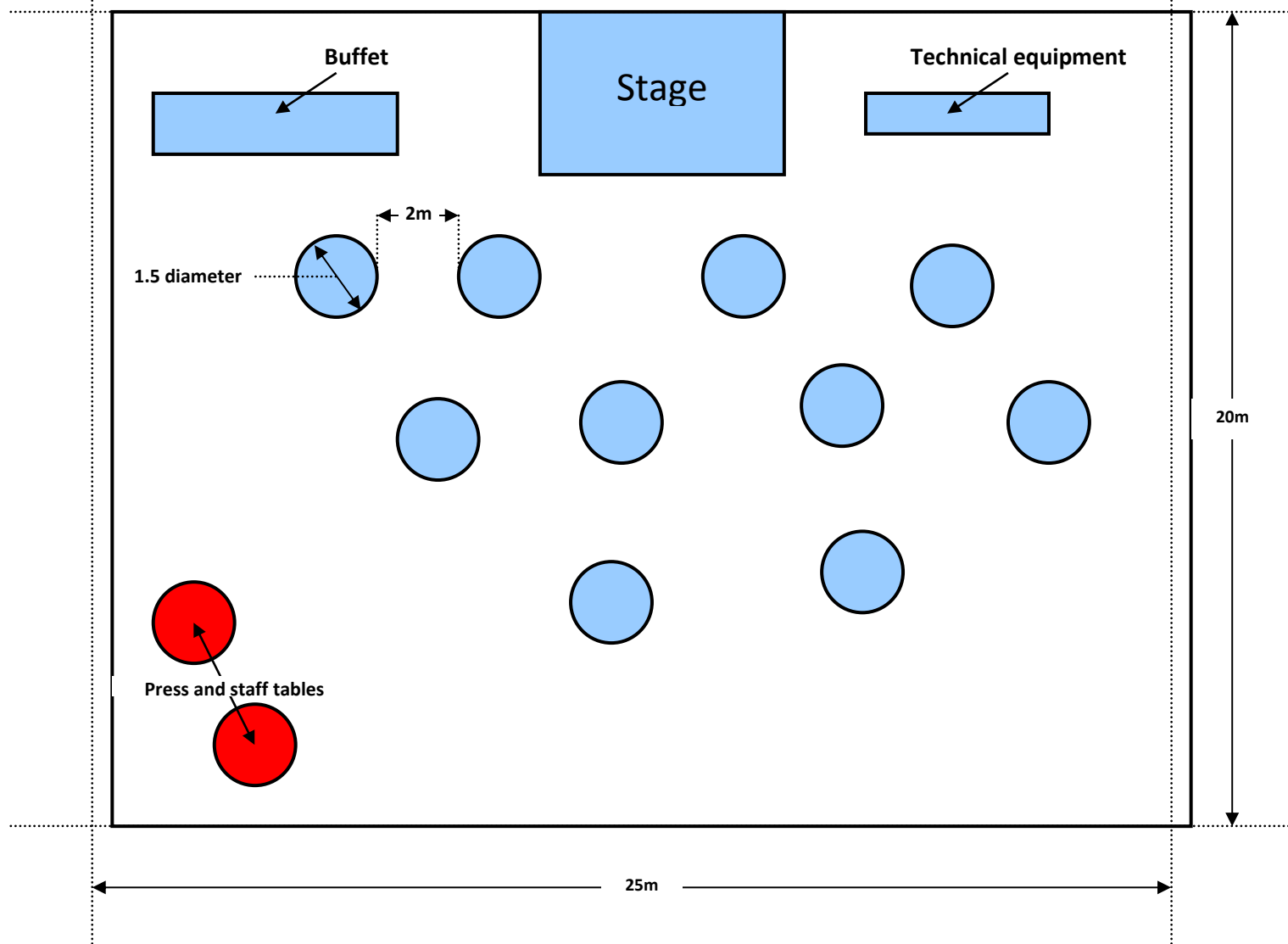
judge that participants from a minority or marginalized group will have difficulties with engaging in a free and open dialogue with the other participants, you can then use different methods to include them in the deliberation. One method could be to put two citizens from the same marginalized group together at the same table in order for them to support each other and feel more comfortable. If you need to take matters further you can create separate spaces for the marginalized group by allocating a separate table for them in order to create a safe environment for their deliberation. However, creating separate spaces for deliberation come at the cost of sharing their views with the other participants. If you want to use such methods to include all participants in the deliberation you need to obtain an approval from the DBT, because it deviates considerably from the principal methods of the project, and we need to ensure consistency across all nations.

Proposal for plenary room arrangement

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(Approx. 250 square meters)



Items and materials you need for the citizen consultation

To be printed before:

- Table numbers to put on the round tables
- "Rules for good dialogue" to put on the round tables (see page 23)
- Copies of the information material, in case some citizens did not bring their own
- Copies of voting papers
- Name tags for citizens
- Name tags for group facilitators and all other staff: Make sure these are different from citizen name tags – (e.g. another colour)
- A sign for the plenary entrance (if necessary)
- A list of participants

Available at each round table:

- 2 sheets of “Rules for good dialogue”
- A paper describing the group facilitator role (see description of role in (page 19)
- 8-10 notepads + pencils/pens

For distribution at check in:

- Name tag with table number
- Folder with:
 - Programme for the day (SHORT version – see example at page 40)
 - Voting papers (one for each thematic session – see page 42)
 - Participant list (if this is the general practice in your country)
 - Reimbursement forms (if you reimburse their transport expenses)
- Copy of the information material, in case the citizens have forgotten their own

Arrival – check in



Name tags, folder etc. at the check in



Table number, note pads, pencils, etc. at the tables

STAFF NEEDED FOR THE CITIZEN CONSULTATION

Staff needed for the citizen consultation:

- 1 Project manager
- 1 Head facilitator
- 10 Group facilitators
- 3 Vote reporters
- 1 Technician
- 1 Media assistant
- 1 Physical exercise instructor
- Catering staff

Some of the staff members have to be able to take care of multiple tasks. You therefore need to make sure that your staff is flexible and willing to carry out other tasks – For example you need some staff members to carry out citizen check-in in the morning, this could be done by the vote reporters.

Project manager: The project manager's main responsibility is to make sure that the citizen consultation proceeds according to the method described. She/he should have the overview of all tasks, and make sure that everything is executed as planned.

During the citizen consultation, citizens may need to clarify certain facts in order to have a fruitful deliberation. To answer these questions, the project manager should work as a knowledge person: If a citizen has a question that cannot be answered by others in his group, the group facilitator can contact the project manager. The project manager will then come to the table and answer the question. He or she should be aware that they must base the answer on facts (contrary to opinion) as much as possible, referring only to the facts presented in the information material. The project manager should have read and understood the information material and be able to answer questions relating directly to its content. He or she does not have to be able to answer questions outside the scope of the information material and – if that is the case – should not answer that kind of questions anyway. This is to make sure that all citizens around the world receive the same information. External scientific experts are unnecessary and should under no circumstances be used as knowledge persons.

It is very important that the project manager makes sure that all other staff knows what to do. This could be done at a training day where all staff runs through every procedure of the citizen consultation. When educating the staff you should hand out relevant chapters and scripts from this manual to them, e.g. the group facilitators should know the voting procedure (see page 24) and make sure all staff receives the relevant scripts. *See script for the project manager in Scripts for ASSET Citizen Consultations, page 41 (forthcoming).*

Head facilitator: The citizen consultation is facilitated by the head facilitator whose main responsibility is to make sure that everybody in the room feels welcome and that all citizens understand what to do and do it within the given time frame. The head facilitator will instruct everyone in the room about what exactly to do every time a new session begins. The head facilitator can be someone from the national partner organization or a professional facilitator hired to do the job. It could also be the project manager, but this is not recommended, since the project manager needs to have the full overview, which can be difficult if you also have to facilitate. In either case it is important that the facilitator is not someone working professionally with epidemics and pandemics. *Script for head facilitator is available in Scripts for ASSET Citizen Consultations, page 41 (forthcoming).*

Group facilitators: There will be one group facilitator at each table. Their job is to function as a neutral moderator of the deliberations at the table. The Group Facilitator's main role is to make sure that the citizens' focus on the assigned discussion theme and that all citizens at the table have a say. They should also keep track of time. It is important that the group facilitators understand and accept that they are not there to state their own opinions, but to help citizens state theirs. Citizens should be able to consider them as neutral, and they should therefore not come from e.g. an organization, which could be accused of being biased, or wear clothes that could send signals to the citizens that they should vote in a certain way, e.g. t-shirts advocating anti-vax etc. They should definitely not be experts on any health related issue debated on the citizen consultation. Furthermore, they may only answer factual questions from the citizens if the answer can be found in the information material and they may not vote or take part in the discussions in any way – other than to facilitate it. It is necessary to train the group facilitators before the citizen consultation. Go through the guidelines together with the group facilitators before the citizen consultation in order to develop a common understanding of the rules. Make sure to engage some extra in case of illness, etc. The group facilitators at each table can be employees in the national partner organizations, volunteers from various organizations, or graduate students. *A more detailed description of the group facilitator's role and script is available in Scripts for ASSET Citizen Consultations, page 41 (forthcoming). See the rules for good dialogue at page 23.*

Vote reporters: The role of the vote counters is to collect voting slips from the group facilitators, type in the results to the web tool, and check that all voting slips have been reported. When they receive the voting slips from the tables, they'll start to report the votes from each individual citizen into the webtool. During the day they should also print the results from the thematic sessions with the purpose of handing them out to the citizens at the end of the day. These prints should be made as the voting results are collected throughout the day. As soon as the results from a thematic session are ready, print them. There will not be time in the end to print them all at the same time. Since they have to work with technical equipment – computers with Internet access and a printer – they

should test this before the citizen consultation, and therefore they should also be in dialogue with the technician. *See page 24 for more instructions on the role of the vote reporter*

Technician: This person makes sure that the technical equipment runs perfectly well during the entire citizen consultation. Please see page 14 where it is explained what technical equipment is necessary. The technician must prepare and make sure to test all equipment before the citizen consultation starts and preferably one or more days before the citizen consultation starts, so that you have a chance to react on any faults. If you decide on having a trial run of the event, it would be a very good idea to have the technician to participate in the trial. The technician should be familiar with the software and hardware that you choose to use. *A script for the technician is available in Scripts for ASSET Citizen Consultations, page 41 (forthcoming).*

Media assistant: This person is responsible for undertaking media related tasks during the citizen consultation. She/he should take pictures to visually document the citizen consultation, take care of the press if any journalists or photographers show up, help do the press briefing, and carry out video interviews with citizens in continuation of the citizen consultation (see dissemination strategy in Part 3). *No script for this task.*

Physical exercise instructor: It is a long day for many of the citizens to sit still and discuss, and especially after the lunch the energy can be low. We therefore have a 5-10 min session during the afternoon program where we get the citizens to move and stretch. A member of the staff (or an external instructor) should beforehand prepare some kind of physical exercise program to execute halfway into the citizen consultation. *No script for this task.*

Catering staff: Following the program at page 40, you need to serve food and/or drinks at least three times: Morning coffee & tea, lunch, and some kind of take away food at the end of the day. You need staff for this, which could be someone already working at the venue. *No script for this task.*

Remember to test all procedures beforehand and pay special attention to matters like:

- Technical equipment
- Facilities
- Room set-up (auditory and visual conditions, etc.)
- Agreements with external personnel (catering, transportation, etc.)



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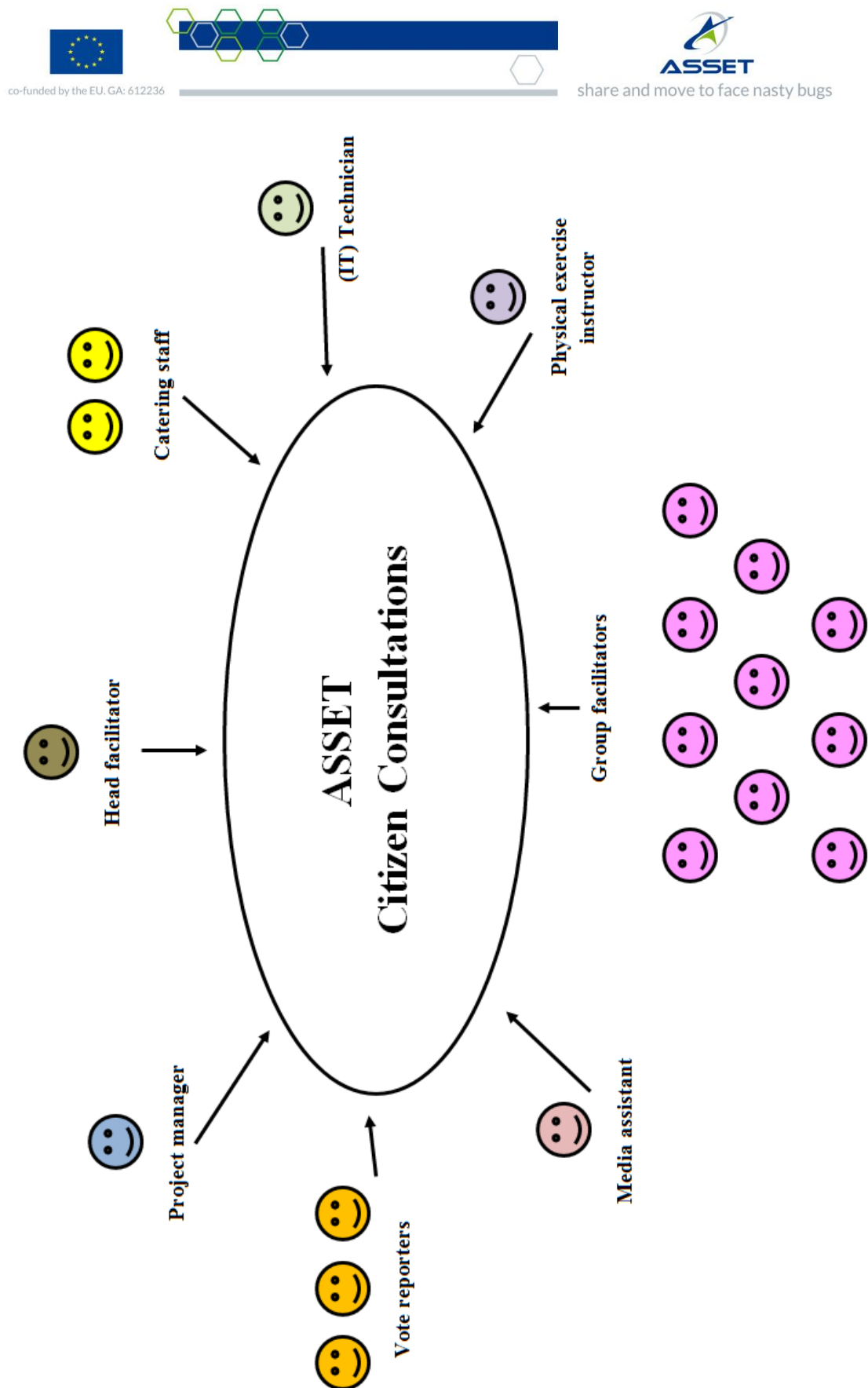


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At the citizen consultation on September 24th, all members of the staff (including group facilitators) should carry nametags, which are different from the citizens, so that citizens will be able to recognize them easily.



Staff for ASSET Citizen Consultations



RULES FOR A GOOD DIALOGUE & DELIBERATION

It is vital that the citizens feel respected and are comfortable with engaging in the dialogue at the citizen consultation. You should therefore encourage the deliberation process by making sure that participants are familiar with the rules for good dialogue. The rules are:

Rules for a good dialogue:

- Think as a citizen/member of the community and not solely on personal interest
- Treat everyone with respect
- Listen carefully to what others have to say
- Do not interrupt each other
- Take part in the discussion
- Focus on the subject
- Keep comments brief and to the point
- Take a break when you need to
- The group facilitator decides whose turn it is to speak
- The group facilitator is neutral and doesn't participate in the debate

The rules should be announced in plenary by the **head facilitator** and thereafter it is the responsibility of the **group facilitators** to make sure the rules are followed at each table. It is important to make sure that the participants feel free to speak and express their views in the dialogue at the table. A print of the rules should be placed on each table to remind everybody to follow them.

Regarding the word 'deliberation', there might not be any point in mentioning this word. It might make the whole thing very intellectually complex, and you do not want that. Instead the head facilitator should try to describe the idea/logic with more simple language and examples. An example of this is illustrated at the end of the script for the head facilitator (**forthcoming**).

VOTING PROCEDURE

At the beginning of each of the thematic sessions the citizens will be presented to the questions of that session by the head facilitator. They will vote individually and anonymously on these questions on voting slips – pre-printed pieces of paper with the questions on. The voting slips must have pre-printed ID numbers, randomly assigned, and the same citizen must have the same ID number throughout the day. This will make it possible for researchers to track the voting of a citizen throughout the day without knowing the identity of this citizen.

We recommend that you put the four voting slips with the same pre-printed ID number in an envelope and randomly hand them out to the citizens at the beginning of the first discussion. However, they must only look at the voting slip for the present discussion, in order not to confuse the discussions.

The voting slip for the first session should include two boxes for the citizens to fill out: gender and age. This is for scientific use, so researchers can track the results of the voting of young people, people in the fifties, compare the voting of men and women, and so on. However, if it is not legal to collect these data in your country, you can proceed without getting information of age and gender. The boxes with gender and age only need to be on the first voting slip, as this will be linked in the database behind the web tool to the ID number.

You need to make the voting slips with questions for each thematic session in your local language(s) and print them for all citizens. You can see an example of a voting slip at page 42 (it is only an example, not questions for actual use).

When the voting slips are completed, group facilitators will collect them and pass them on to the vote reporters. The vote reporters will then type the votes into the web tool one by one and they will immediately be published on the ASSET website. In this way all results will be gathered online for further examination and comparison. All results must be uploaded on September 24th, as soon as the session has finished.

A video guide on how to report the results to the web tool will be made available in June.

TRANSLATING INFORMATION MATERIAL AND QUESTIONS

Prior to the citizen consultation the citizens will receive an information booklet of approximately 30 pages informing them about facts and dilemmas of epidemics and

pandemics. This material will also be available from the project's website long after the citizen consultation. At the citizen consultation information videos will be shown in the beginning of each session. The information videos will provide basic information and the written material will elaborate on some of the information also given in the videos. The information given at the actual citizen consultation (the videos) should in itself be sufficient in order to engage the citizens in a meaningful debate about the questions asked, but the level of the debate will improve if care is taken to make citizens familiarize themselves in advance with the information given in the written material. Citizens that may have problems with reading and understanding the written information material can be encouraged to seek assistance from friends or family. Possibly the national partner could offer assistance from students or other volunteers. They should not be professionally knowledgeable about epidemics and pandemics (experts), but knowledgeable enough to explain the material. The partners could also choose to make a podcast of the written material read out loud in the local language.

All information material will be provided in English and translated by the national partners to their native language. It is a good idea that national partners check their translations with an expert in the field to make sure that the correct technical terms are used in the translation.

Information Booklet

All citizens will prior to the citizen consultation receive an information booklet on epidemics and pandemic of about 20 pages. You will receive the final layout and text for the information material in English early July, which you will need to translate into to your local language and print. This booklet should then be sent to all participating citizens a couple of weeks prior to the citizen consultation.

Video Material

Following the program for the citizen consultation (see chapter 1.5), each of the four thematic sessions should begin with the screening of an information video. The videos are designed to introduce the issues debated in each of the sessions.

The videos will be produced in English. You need to translate them into your local language, you need to record the translation as a sound file, and you need to edit the file to the video. You find a guide for doing so at <https://vimeo.com/124409315>

If you have further questions or need some help, contact the video producers at DBT at jh@tekno.dk

The Questions

The questions that the citizens will vote on will be provided by DBT in English around July. You need to translate the questions into your local language and enter the translations into the web tool before the end of July. As many countries have more official languages, you need to send an email to John Haukeland at jh@tekno.dk with information on which language(s) you will use in your meeting on September 24th and need access to translate into in the web tool. You will then receive a personal link for the translation part of the web tool and a video tutorial explaining how to upload your translation.

We will provide the questions in English. If you host your meetings in this language, you do not have to translate the questions – but we still need you to send the email telling us which language(s) you will use for the day to give you access to them.

You also need to send the translated questions in a word file to DBT: jh@tekno.dk

Please note, that the questions are secret and must not be revealed to the citizens, media or general public before September 24th.

What you can tell about the questions and information material

The questions that citizens across Europe will vote on play a central role in ASSET. They define the topics that will be deliberated on and frame the subsequent voting results. The information booklet plays a complementary role in the sense that it enables citizens to reflect on the four themes, and then make up their own mind and vote on an informed basis.

Therefore, the production process included several rounds of feedback and input from a wide array of stakeholders, in order to make the questions and information booklet as balanced and impartial as possible.

PRACTICAL ARRANGEMENTS FOR THE CITIZEN CONSULTATION

TRANSPORT AND ACCOMMODATION

It is important to explain in details to the citizens how to get to the citizen consultation venue. In some cases it can be necessary for you to organise different things, so that it is

easy and affordable for the citizens to participate in the citizen consultation. You can consider some of the following things:

- Organising transport by bus from central meeting points.
- Providing free parking space for private cars.
- Refund transport expenses.
- Arrange accommodation for those who may need it.

Some citizens travelling from far and wide may need accommodation. As a courtesy to them you could help them find accommodation (maybe even pay for it, if your organisation can afford it). Remember to book accommodation for members of the staff if they need to arrive at the venue a day in advance.

CATERING

Food and beverages are essential to the success of the citizen consultation. The participants should have access to a varied and changing buffet throughout the whole day, so that they have the necessary energy to deliberate. Some participants may have personal needs concerning the food. There might be people suffering from allergies (lacteous, gluten, etc.), vegetarians, and citizens with religious limitations on food. In order to meet special needs, citizens should be given the opportunity to declare these needs when they send in the application form for attending the citizen consultation.

The all-day accessible buffet should consist of:

- Breakfast
- Lunch
- Fruits, snacks & sweets, coffee, tea, soft drinks, water available all day
- Take away food when the citizen consultation closes

Dining facilities such as plates, glasses, cutlery, etc. should be in place. Often personnel at the venue will take care of the catering. Make sure that there also are personnel that can help clearing the tables during the day.

BREAKS

There are no scheduled breaks in the programme. This is because it might interrupt the dialogues and debates. Secondly scheduled breaks might pose serious practical problems: It is not a good idea to have all participants going to the restroom or taking a smoking break at the same time – it simply gets very crowded and takes too much time. We



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therefore strongly recommend not having any kind of scheduled breaks during the day – including eating breaks. This requires that you make sure that the citizens are informed that they should take their own breaks. A good idea could be to get the group facilitator to arrange the breaks at the table, so that the table takes a break at the same time, but not at the same time as all the other tables. The group facilitator should also make sure that citizens do not take a break just as we are about to vote. If you would like to include a “real” lunch break, then you have to prolong the day, as the programme and time allocated for the sessions should not be shortened.

PHYSICAL ACTIVITY

When DBT holds a citizen meeting, similar to this citizen consultation, an important element of the program is physical activity. Mostly conducted from the stage by an actor or fitness trainer that takes the citizens through a 10-minute program of small exercises. Sitting still a whole day can be hard for the body and mind. A little exercise gets the blood pumping, clears the mind, and loosens up muscles, which makes the citizens regain their concentration.

TEMPLATES AND SCRIPTS

FORM FOR YOUR CITIZEN RECRUITMENT STRATEGY

Person(s) responsible for the citizen recruitment for your citizen consultation

Name	email	telephone	responsibility

The criteria's for selection of citizens

Please fill out the information on the population in your country in the questionnaire below.

Age

Percentage of the population are in the age group 18-29	
Percentage of the population are in the age group 30-39	
Percentage of the population are in the age group 40-49	
Percentage of the population are in the age group 50-59	
Percentage of the population are in the age group 60-69	
Percentage of the population are in the age group 70+	

Geographical zone (you should change the categories so that they match the categories relevant in your country)

Percentage of the population who lives in the city	
Percentage of the population who lives in smaller towns	
Percentage of the population who lives in villages	

Percentage of the population who lives in the countryside	
Other characteristic which describes the geographical zones of the country?	

Educational level (you should change the categories so that they match the categories relevant in your country)

Percentage of the population whose has not gone to school	
Percentage of the population whose highest education is primary school	
Percentage of the population whose highest education is high school	
Percentage of the population whose highest education is university?	

Occupation (you should change the categories so that they match the categories relevant in your country)

What are the six main occupational categories in your country? (E.g. education, farming, fishing, healthcare, finance etc.) And how big a percentage are they?	<ol style="list-style-type: none"> 1. 2. 3. 4. 5. 6.
What is the unemployment rate in your country?	

Gender (if different from 50/50)

Percentage of the population	
------------------------------	--



who are women	
Percentage of the population who are men	

Criteria of national relevance

Any other criteria of national relevance? (E.g. Religion, ethnicity etc.)	Yes / no
If yes, please specify	

Source(s) of data

Where have you found the data?	
--------------------------------	--

D. The recruitment of citizens

Which method(s) will you use to recruit the citizens? (see manual)	
What is the time frame for the different steps in your citizen	



recruitment?	
What will be the biggest challenge in making the participants reflect the general population in your country?	
How do you plan to manage this challenge?	
Will you recruit citizens from all parts of your country or from a region? Please specify	
Other considerations you have made regarding your citizen recruitment strategy?	

EXAMPLE OF LETTER OF INVITATION

<Add citizen name and address>

ASSET - We need your opinion!

Dear <Name>

<Organization name> invites you to participate in a citizen meeting on epidemics and pandemics:

Saturday September 24th 2016 at <time>

at the <name and address of the meeting location>

On September 24th 2016 hundreds of citizens across Europe will meet to discuss and vote about the same questions. And you are invited to be one of them.

You will together with 50 other citizens in <country> meet and exchange views on epidemics and pandemics; how should the political leaders deal epidemics and pandemics and what should the policy makers due in this regard? Tell them your opinion – we will make them listen!

You do NOT need any special knowledge about epidemics and pandemics in order to participate. The idea is to bring the views of lay people to the decision makers. We will prepare you with basic knowledge before the meeting by <add your way of communicating the information booklet knowledge – will you upload podcasts before September 24th?>. At the meeting, you will through the day be guided with video clips, debates and votes.

Attendance at the citizen consultation is free. Enrolment, however, is necessary and we need to receive confirmation of your participation before <add your deadline>. On the next page you will be able to read more about the meeting and enrolment procedures.

Turn your thoughts into action by letting national and international politicians know what you think. We hope you would like to participate in our meeting.

Best regards

<Sign with name and organization name>

See next page

A network of organizations including *<your organization>* has joined this European project in order to include public opinion in the European policy making about epidemics and pandemics. It is the politicians who are going to decide on the future of the world but it is you as citizens, who have to live with the consequences of these decisions.

Why do we write to you?

September 24th 2016 eight citizen consultations - with 50 participants each - will be carried out in countries across Europe. You are one of the chosen few who are invited to participate in the *<your country>* citizen consultation. At the citizen consultation we will put together a broad and varied section of the population.

If we receive more confirmations of participation than needed, we will choose the participants so that they make a broad and varied section regarding such things as age and gender. You will be notified about your participation at the latest on *<pick and write a date for this>*.

About the citizen consultations

At the meeting you will go through different sessions, each introduced with a short video clip. You are going to sit together with 5-6 other citizens around a round table and have the opportunity to discuss with them and vote about certain important issues. The results of the votes will be announced on the day. The meeting day puts citizens at the center without interventions from politicians and experts.

Food and beverages are free and available the entire day.

Enrolment

Attendance is free but enrolment is necessary. Fill out the enclosed form and return it *<proposal: in a stamped and addressed envelope>*. Your enrolment has to be in our hands *<pick and write a date for this>*.

<write your plans for transportation and accommodation>

After the confirmation deadline we will *<write how you are going to enlighten the participants before the meeting – are you going to send them a translated copy of the information material, making community discussions, etc.>*

Who is behind the project?

ASSET is organized by a group of European organizations – which *< your organizations name>* is part of.

The project is financed by the EU-Commission.

Any questions?

Do you have any questions related to the project and your participation in it, you are welcome to contact: *<write name, address, e-mail, phone number on the person to contact>*

See next page



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Enrolment form:

I wish to participate in the ASSET citizen consultation on September 24th 2016 from <time> at <add name and address of the meeting location>. Participation is free but enrolment is necessary on <add a date for the enrolment deadline> at the latest.

(Please fill out the entire form)

Name: _____

Address: _____

<this next section depends on what you choose to do in relation to chapter 11>

Transport <if you offer coaches or anything similar to pick up citizens you need a feedback section for this> (tick off)

I will find transportation myself ☐

I wish to use one of the coaches ☐

<if the citizens wish to transport themselves, you can offer them compensation>

Accommodation <if you offer accommodation you need a similar feedback section as to "Transport">

Personal Information (tick off)

Gender: Female ☐

Male ☐

Age: 18-29 ☐ 50-59 ☐



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30-39	<input type="checkbox"/>	60-69	<input type="checkbox"/>
40-49	<input type="checkbox"/>	71+	<input type="checkbox"/>

Occupation (job): _____

In what region do you live? (tick off) *<you should consider to have categories corresponding to relevant national differences between city / country side etc. >*

A	<input type="checkbox"/>	B	<input type="checkbox"/>	C	<input type="checkbox"/>
D	<input type="checkbox"/>	E	<input type="checkbox"/>	F	<input type="checkbox"/>
G	<input type="checkbox"/>	H	<input type="checkbox"/>	I	<input type="checkbox"/>
J	<input type="checkbox"/>	K	<input type="checkbox"/>	etc.	<input type="checkbox"/>

<you should add categories corresponding to your recruitment categories. This could be of ethnical/regional differences, for example:>

Education: _____

What ethnic group do you belong to? (tick off)

A	<input type="checkbox"/>
B	<input type="checkbox"/>
C	<input type="checkbox"/>
None	<input type="checkbox"/>



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Other: _____

<as mentioned in the “Letter of invitation”, you may also ask for special needs concerning catering (allergies, vegetarian, vegan, kosher, etc.)>

EXAMPLE OF LETTER OF CONFIRMATION

<Add citizen name and address>

ASSET

Dear <Name>

We would like to thank you for your enrolment to the ASSET citizen consultations, which will take place:

***Saturday September 24th 2016 at <add time>,
at the <name and address of the meeting location>***

This letter confirms your participation at the consultation. We are very happy that so many citizens from <country> have shown an interest in discussing epidemics and pandemics. All slots are now filled and we close for further sign ups.

Enclosed you will find different material about the day and about epidemics and pandemics, so that you have the opportunity to prepare for the day and how to prepare:

- Information about the project
- Program for the day <short version>
- Transport information on how to get back and forth to <add location name>
- Accommodation information <add name of hotel or the like if offered>
- Information material for you to read before the consultation

Important: Please notify us at <add telephone number and/or e-mail address> if you for any reason are prevented from participating in the consultation. <so you can adjust your number of participants>

We look forward to see you at the citizen consultation and we hope for an interesting and rewarding day with good dialogue. Please do not hesitate to contact us if you have any questions.

Best regards

<Sign with name and organization name>

See next page

<on the next pages you should inform more detailed about the meeting program, transportation, accommodation, information material etc. Especially you should



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*inform about the importance of reading the information material and how you
will assist the participants in this before the meeting>*

LETTER TO NON-SELECTED

< Add citizen name and address>

ASSET citizen consultation is fully booked

Dear <Name>

We thank you for your interest and your enrolment to the ASSET citizen consultations. Unfortunately we have received more enrolments than we can accommodate, and we therefore have to disappoint you, as we cannot give you access to the consultation.

We only have room for 50 citizens at the consultation, and because we received more enrolments than that, we had to select between the applicants to ensure an as mixed group of citizens as possible. Unfortunately there were a lot of enrolments of people with-in your <age /or other criteria> and <gender /or other criteria > and we therefore have decided that you will not be able to participate at the consultation.

You can find information about the consultation and the project at our national website <add your sub-site address> and international website <forthcoming>.

If you have any questions regarding ASSET, you are welcome to contact <write name, address, e-mail, phone number on the person to contact>.

Best regards



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<Sign with name and organization name>

EXAMPLE OF THE SHORT PROGRAM

ASSET Citizen Consultations

Program for ASSET in XXX (Country)

Saturday September 24th 2016 at XXX (Venue)

- | | |
|----------|---|
| 9:30am | Citizen check-in opens |
| 10:00am | Welcome

by XXX (Prominent and relevant speaker)

by XXX (Head facilitator) |
| 10:30am | First thematic session - Personal freedom and public health safety <ul style="list-style-type: none">• Introduction of the theme and video presentation• Debate at the tables• Voting |
| 11:30 pm | Second thematic session - Communication between citizens and public health authorities <ul style="list-style-type: none">• Introduction of the theme and video presentation• Debate at the tables• Voting |
| 12:30 pm | Third thematic session - Transparency in public health <ul style="list-style-type: none">• Introduction of the theme and video presentation• Debate at the tables• Voting <p><i>Lunch is served at the buffet.</i></p> |
| 1:45 pm | Fourth thematic session - Access to knowledge <ul style="list-style-type: none">• Introduction of the theme and video presentation• Debate at the tables• Voting |
| 2:45 pm | Open Session |



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- Introduction of the theme
- Recommendations

3:30 pm

Thank you for today by XXX (prominent and relevant speaker) and
XXX (head facilitator)



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SCRIPTS FOR THE CITIZEN CONSULTATION

This chapter contains scripts for the citizen consultation to guide the project manager, head facilitator, technician and group facilitators.

If you have little experience in citizen consultation facilitation of this kind we strongly recommend you to practice the citizen consultation. You could invite all staff to an exercise day before the citizen consultation, so you can try the program together. It is important to make sure that ALL members of the citizen consultation staff (especially the group facilitators) are well educated before the citizen consultation. This is to minimize the amount of possible faults and uncertainties during the citizen consultation.

THE PROJECT MANAGER

This script concerns the task for the project manager on September 24th, 2016. It does NOT include tasks to be carried out by the project manager before and after the citizen consultation itself (preparing, dissemination, etc.). There are important tasks before September 24th, including setup at the venue, furnishing the citizen consultation room, training of group facilitators (see the script for group facilitators), making sure that all work stations at the venue are equipped, test of the technical arrangements, making sure that the venue and toilets are clean etc. Make yourself familiar with the scripts for all staff members. Some of the tasks in this script could also be carried out by the head facilitator. You can divide the tasks with the head facilitator beforehand. Under all circumstances you need to go over the program and script with the head facilitator.



PROGRAMME	TASK	NOTES
Staff briefing	<ul style="list-style-type: none"> – Gather the staff. – Make sure that everybody is there, and if not find substitutes (see chapter 2.3). – Hand out nametags in a special colour to all members of the staff. – Together with the head facilitator you encourage everyone and call for team spirit. – Repeat (very briefly) the roles and tasks of everyone. – Clarify uncertainties and answer questions. – Make sure that all material and equipment is there and is functioning (see chapter 2.2). – Remember breakfast to staff members. 	<p>This is only meant as a short follow up on previous training and briefings to make sure that the staff are present and familiar with their tasks during the day.</p> <p>Use some extra time to repeat the role of group facilitators.</p> <p>All items should be placed correctly in the room, at the tables, at the entrance, etc.</p>
Citizen check in	<ul style="list-style-type: none"> – Make sure that you have staff placed at the entrance to help and guide the citizens and to make sure they receive papers (see chapter 2.2) and their nametags with table numbers. – Make sure that only invited people enter the room. – Make sure that people have some breakfast. – Make sure that members of staff assist participants to be seated at the right tables (max 7 + group facilitator). – Make sure that visitors (journalists, politicians, the prominent speaker, and others) are taken care of and are seated (not at the group tables). 	<p>Participants should get a folder including a short programme for the day, voting papers, and the information material (has been delivered to citizens before).</p> <p>When this session ends all citizens and group</p>



	<ul style="list-style-type: none"> – Make sure group facilitators go to their table 	facilitators should be seated at round tables.
Introduction	<ul style="list-style-type: none"> – Start the programme by letting the prominent speaker begin. – Make sure that the speaker keeps the time. – Introduce the head facilitator who will lead the plenary sessions from now on. 	Even though you give the platform to the head facilitator, you will still be the person responsible for taking decisions about possible issues that arise during the day.
First thematic session;	<ul style="list-style-type: none"> – Make sure that the programme and time schedule is followed. – Make sure that all members of the staff actively fulfil their tasks. This implies that video clips are ready on time; that results are reported correctly, etc. – Answer questions from the tables related to the information material that the group facilitator cannot answer. NO QUESTIONS IN PLENUM. 	<p>During the group discussions you should circulate discretely around the room and make sure that the group facilitators fulfil their task and that discussions goes successfully.</p> <p>Keep an eye on the voting procedure and assist if necessary. This part is very important.</p>
Second thematic session;	<p>Same as above</p> <ul style="list-style-type: none"> – Make sure that the vote reporters have started to type in the results 	
Third thematic session;	<p>Same as above</p> <ul style="list-style-type: none"> – Make sure that the vote reporters have started to type in the results 	When lunch is available you help facilitators to make sure that everybody does not collect their food at the same time, but that lunch pass off smoothly without interrupting the sessions.



Fourth thematic session;	<p>Same as above</p> <ul style="list-style-type: none"> – When you (together with the head facilitator) find it appropriate (for example before third thematic session) you should start the physical exercise. – The physical exercise instructor should arrive in good time before the exercise takes place. It is possible that the instructor is bringing a tape or CD with exercise music. <p>Make sure that the vote reporters have started to type in the results</p> <ul style="list-style-type: none"> – Make sure that the vote reporters have started to type in the results 	Be sure that the technical staff supplies the instructor with the equipment he needs (for example, a microphone, CD-player, etc.).
Fifth thematic session;	<p>Same as above</p> <ul style="list-style-type: none"> – Make sure that the vote reporters have started to type in the results 	
Closing remarks	<ul style="list-style-type: none"> – Enter the platform and tell citizens about procedures to follow up from the citizen consultation. Citizens need to know: <ul style="list-style-type: none"> ○ How they can keep themselves updated with the results. ○ How the results are communicated to policy makers. ○ Practical issues (home transportation, take away food, etc.). – You can inform about results from other countries (for example screen shots from the website.) – You and the head facilitator say thank you to the participants. – Maybe some of your staff members could make video interviews with a few citizens about their participation. 	



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THE HEAD FACILITATOR

This script concerns the task for the head facilitator at September 24th 2016. You have also other tasks related to preparing the citizen consultation, for example, practice the program together with the other staff members and briefing the group facilitators (together with the project manager) etc. In order to lead the citizen consultation you will need to know the scripts and tasks for all other staff as well.

Some of the tasks in this script could as well be carried out by the project manager. You can arrange with the project manager (beforehand) who is doing what. In all circumstances you need to go over the program and script with the project manager.

PROGRAMME	TASK	NOTES
Staff briefing	<ul style="list-style-type: none"> – Gather all staff. You assist the project manager in this session to encourage everyone and call for team spirit. – Make sure you are familiar with everyone's role and tasks during the day. 	Important that all staff members get confident with you as you are the one to lead them during the day.
Citizen check in	Preparations: <ul style="list-style-type: none"> – Get microphone from tech staff and do a sound test – Organize your papers at the platform – Welcome people and help to make sure that everybody gets their intro-package, name badges and that they are seated at the right tables etc. 	
Introduction	After the prominent speaker leaves the platform you lead the citizen consultation. <ul style="list-style-type: none"> – Introduce yourself and tell about the roles of the different staff members (especially the group facilitators). – Give practical information (where are the toilets, where to get coffee, tea or water, rules for smoking, mobile telephones should be turned off etc.) – Speaks about the principles and purpose of deliberation and you introduce the citizen consultation programme (only main points; 	You should have prepared yourself carefully for this session as it is crucial that people in the room feel confident with you and that the participants gets energy and drive. No questions in plenum , all questions should be given



	thematic sessions, no common breaks but they should arrange this at the tables)	to group facilitators who can call for assistance. When you explain deliberation the proposed text at the end of this script is good to use.
First thematic session;	<p>First you give an overview of the procedure with the three steps (the procedure is the same for all thematic sessions): Step 1, Introduction of the theme and a video presentation. Step 2: Discussions at round tables. Step 3: Voting (voting papers in intro-packages). (Max 10 minutes for this total overview).</p> <p>Then you start the procedure:</p> <ul style="list-style-type: none"> – Step 1: You introduce the theme of the first session (1 minute) and you show the video clip (normally about 5 minutes, but in this 1st. session about 8 minutes). – Step 2: You start the round table discussions and request the group facilitators to start with an introduction round, where everybody tells who they are and what their first impression is about what they saw at the video (45 minutes). – Step 3: You announce the voting and repeat the voting procedure (see chapter 2.4) (about 15 minutes). 	<p>When you explain the procedure you should have an overhead / power point showing the 3 steps.</p> <p>There should be no questions in plenum but make sure that members of staff help the group facilitators when needed (especially regarding the voting procedure).</p> <p>You should have a power point showing the questions that structure the discussions (NB: not the same questions as the voting questions)</p> <p>Sometime before step 2 (table discussions) ends you should remind the group facilitators to make sure all main elements are touched upon.</p>
Second thematic session;	You start the procedure as above (the 3 steps), but now without the overview of the procedure	<p>Results presentation:</p> <p>It will be an advantage if you can present the voting</p>



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		<p>results on power point.</p> <p>If results from the 1st session have been reported in good time (30 min before) via the webtool, you can show participants the results on the webpage. (Simply go to the results page and select your own country and language, and a graphical presentation of results will be available).</p>
Third thematic session;	<p>You start the procedure as above (the 3 steps), but now without the overview of the procedure</p> <ul style="list-style-type: none"> – Step 1: 5 minutes – Step 2: 45 minutes (including time to get lunch) – Step 3: 15 minutes (including results - see below) – Introduce that lunch will be available from a buffet and should be taken to the tables when people are ready to eat - not simultaneously. Emphasize that there's no break involved, citizens are supposed to dine while the session is running. – Before step 3 (voting) you present the results from the voting in first and second session (about 5 minutes included in step 3). 	
Fourth thematic session;	<ul style="list-style-type: none"> – You start the procedure as above. – When you have the feeling that people get tired you arrange with the project manager to start the 10 minutes physical exercise. You give the floor to the instructor. – Before step 3 (voting) you present the results from the voting in third session (5 minutes). 	<p>10 minutes exercise; will take about 15 minutes before people have returned to the tables and you can continue.</p>
Fifth thematic session;	<p>First you give an overview of the procedure with the three steps: Step 1,</p>	



	<p>Introduction of the session.</p> <p>Step 2: Discussions at round tables.</p> <p>Step 3: Writing recommendation and highlighting key words.</p> <p>Then you start the procedure:</p> <ul style="list-style-type: none">- Step 1: You introduce the format of this last (and 5th) session (3-4 minute).- Step 2: You start the round table discussions and request the group facilitators to start with an introduction round, where everybody tells what their most important takeaway is from today, and which discussions they found most interesting (10-15 minutes.)- Step 3: You announce that it is time for writing recommendation and highlighting key words (25 minutes).	
Closing remarks	You thank the participants for their active contribution to the project, and then you give the platform to the project manager.	You should actively support the project manager during the rest of the program.

Example of how head facilitator can introduce the idea about deliberation without using the technical term “deliberation”:

Dear participants,

Today you are going to share your views on epidemic and pandemic preparedness and response.

In order to give you the best thinkable basis for stating your views, we have gathered a lot of different information from different sources pointing in different directions. This has been presented to you in the information material that you received before the citizen consultation and we will also show you some videos today.

We have invited a broad variety of citizens, broadly representing all parts of society. You have been invited as citizens because you all come with different experiences on and knowledge of epidemics and pandemics and you all have different stories to tell.

Today you will listen to and discuss different facts and statements. You may agree with some and disagree with others. You do not need to reach a common agreement at the table as you will all vote individually, but it is important that you listen to each other and respect each other's opinions. At this citizen consultation everyone is equal, free of hierarchy, meaning that anyone can put forth proposals, criticize, and support measures.

We believe that the best way to discuss and consider an issue is to look upon and assess as many aspects of the issue as possible. That is the reason why we bring so many differences into play.

At your table you have a group facilitator. His/her job is function as a neutral moderator of the dialogue at the table, and they are not allowed to state their own opinion.



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THE GROUP FACILITATORS

This script concerns both a part describing the **role** of the group facilitators and a part with the **tasks** for the group facilitators on September 24th 2015.

The group facilitators should read the role description (see **chapter 2.3**), the script (table with tasks below) and the information material given to the citizens thoroughly before the citizen consultation.

The whole idea with the dialogue at the table is not to get everybody to agree, but that the citizens hear different perspectives and different points of views in order to reflect on their own view.

Group facilitators' role

As the name indicates, the group facilitator will have to manage (facilitate) a discussion between a group of 6-7 participants. The four thematic sessions will each consist of discussions followed by a voting sessions.

The group facilitators have an important role in the discussion process. The group facilitators make sure that the discussions sticks to the point and progress in a good and matter-of-fact form. The facilitators should not influence the process with personal points of view and should avoid using their knowledge about the subject to promote their own views in the table discussion.

The group facilitator is in charge of the table and should act like that. Dominant citizens have been seen to take control over the table, which is why the group facilitator should be able to maintain the facilitator role and demonstrate who is participant and who is running the debate. It is your most important job to make sure that everyone at the table gets a chance to state their opinion. This means that you have the right to stop a discussion in order to give room for somebody to be heard.

The debates at the tables should start out relatively open discussing the overall theme for the session. Then the table facilitator should move the discussion more towards the voting questions. The citizens should not look at the voting questions before the last third of the discussion, and you should not go through the questions and answers options from one end to another, but the group facilitator must structure the deliberations so that all questions in the thematic session are



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properly debated. If the debate dries out, e.g. the participants agree on the subject within short time; it might be necessary for the group facilitator to use prompting questions to start the debate again. This could be by asking the citizens to look at the theme from a different perspective or by playing the devil's advocate and ask critical question.



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Tasks

As a group facilitator it is your task to:

- Keep the group focused on the task.
- Ensure participants treat one another with respect.
- Enable everyone to participate.
- Handle the speech list order.
- Give every citizen a chance to express their views on the questions.
- Encourage the shy and cautious citizens not accustomed with deliberations like this to express their views.
- Moderate eager citizens and to limit their time to speak, so that everybody can get a fair chance to speak.
- Make sure you stick to the timetable.
- Explain the citizens what the main objectives of the tasks are in case they are in doubt.
- Maintain neutrality.
- Moderate the discussions without promoting your own view.
- Listen and be aware of your authority as a moderator. It is important that you do not influence the discussion by telling about your own point of view or perspectives.
- Remember that the participants are here as lay people on the topic and therefore they will express themselves on that background. This is the main idea of the project, so it is important that you do not use valuable time from the group discussions to enlighten/educate the citizens or answer questions on the content.
- Collect votes and counting in cooperation with the group.

You should go through the “Rules for good dialogue” (available on every round table) together with participants (see [chapter 2.6.3](#)).

A way to include all citizens and make sure that everybody is heard is to start the session by giving the citizens a minute or two to reflect on the theme and their own point of view, and then give them 1 minute each to tell about their thoughts. No one is allowed to comment or ask questions before everybody have presented their thoughts. When everybody has had their turn, you can open/start the free discussion.



PROGRAMME	TASK	NOTES
Staff briefing	<ul style="list-style-type: none"> – Attend staff briefing: – It is helpful for the group facilitators to have repeated: <ul style="list-style-type: none"> ○ Practical information such as location of toilets, cloakroom etc. ○ The time schedule for the citizen consultation. ○ The group facilitator's role: manage discussions, prioritize the time, make sure that all citizens have a say, make sure that all questions have been addressed in the discussions, see to that participants are ready for voting. ○ The procedure about voting (read chapter 2.4). 	<p>The group facilitators (and other staff) will receive a name badge to put on the clothes, showing firstly that they are an authority and secondly that they are different from the participating citizens.</p> <p>It is very important for the group facilitator to be familiar with the programme of the day.</p> <p>As there are no scheduled breaks during the day, it is your job to coordinate the breaks at your table.</p>
Citizen check in	Find your table and help citizens find their seat at the right table (a seating plan is made for this purpose).	<p>Introduce yourself and make sure that all participants at your table know that you are the group facilitator.</p> <p>Make sure citizens present themselves towards each other (shake hands) thus a friendly atmosphere is established.</p>
Introduction		If participants at your table have questions, you need to answer these after the introduction. Make sure that



		questions are not asked in plenum.
First thematic session;	<p>After the introduction, the video presentation, and the head facilitators presentation of the questions, you start the discussion:</p> <p>Discussion: The group facilitators start the discussion at the table with an introduction round, where every participant one by one presents themselves and say what their first impression is about what they saw at the video – max 1 minute each. After that you should lead the discussion as prescribed in the group facilitator's role description above.</p> <p>Voting: At the end of the discussion, you go through the voting procedure as described in chapter 2.4.</p>	<p>Make sure that the discussion questions in this session have been discussed within 45 minutes. (NB: the discussion questions are not the same as the voting questions)</p> <p>The citizens should <u>discuss</u> together – not ask questions towards you. If they ask questions, you should make answers corresponding with the information material. As a last way out, you should call for the project manager to answer.</p>
Second thematic session;	– Same procedure as first thematic session	Make sure that every discussion question in this session has been discussed and voted on within 45 minutes .
Third thematic session;	– Same procedure	<p>Make sure that the discussion questions in this session have been discussed within 45 minutes.</p> <p>Lunch is served at the buffet. People consume at the round tables while the thematic sessions are running. No definite break involved. Make sure this will happen</p>



		smoothly, with least interruption for the citizen consultation.
Fourth thematic session;	– Same procedure	<p>Make sure that every discussion question in this session has been discussed and voted on within 45 minutes.</p> <p>After the exercise, you have to make sure that the participants find their seat right away.</p>
Fifth thematic session;	<p>For question 5 we have developed a method for analyzing the answers from the citizens. After answering the question, citizens will be instructed to encircle the 2-5 most central words in their answers. Our reason for this choice is that it provides us with an opportunity to go through the answers from the citizens more quickly than if we have to read through all the answers and then try to structure them. We have made instructions for the citizens on how to encircle the answers and what constitutes central words in an answer. Having encircled specific words in their answers the citizens answer data will then be inputted in a table.</p>	<p>Practice this exercise once or twice before citizen consultations, so you will feel accustom with the approach.</p> <p>The questions is:</p> <p>In this session we would like you to answer the following question:</p> <p><i>Considering the issues debated today, what is your most important recommendation to national and international policy-makers?</i></p> <p>For this last question, question 5, what we would like you to do is, after answering the question, encircle the 2-5 most central words in your answer. By central we mean words that denote what your answer is relating to,</p>



		<p>some central actors and the main focus moving forward. Below is an example on how that could look:</p> <p>In a crisis situation such as a pandemic I think the government should improve their communication to the citizens to make sure everybody knows what is going on in a given situation and how they should handle it.</p> <p>Marking these 3 words highlights the main proposal in this answer. The reason we would like you to do this is that this is a great way of preparing the data for further analysis.</p>
Closing remarks	When the citizen consultation is finished thank the citizens at your table for a pleasant day.	

THE TECHNICIAN

The technician should be familiar with the software and hardware used at the citizen consultation, and should be the one to make sure that all technical equipment is running perfectly during the entire citizen consultation. Please consult [chapter 2.2](#) that explains what technical equipment is necessary. The technician must prepare and test all equipment before the citizen consultation will start. If you decide on having a trial run of the event, the technician should of course participate.



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Some issues that should be addressed before the event starts could be: Is the computer used for the power point and video presentations able to work with the projector and audio system? Do the microphones work probably and with good sound quality? Do the sound from the introduction videos? Does the internet connection work? Are you able to connect to the web-tool? Is the printer able to print out copies of the results for all citizens? Questions like these are good to think through so that you are well prepared for the citizen consultation.

PROGRAMME	TASK
The day before	<ul style="list-style-type: none"> – Technical Set-Up: If it is possible computers and audio & visual equipment should be set up the day before and tested. Please test as much as possible the day before, such as; correct connection to the internet, computer batteries should be fully charged or plugged in, proper set-up of video-playing-equipment to the screen or TV, good set-up of the microphone to the audio system, power-points should be put on the computers used.
Staff briefing	<ul style="list-style-type: none"> – Attend the briefing
Citizen check in	<ul style="list-style-type: none"> – Make sure that all technical equipment is ready. What technical equipment has to be ready next?
Introduction	<ul style="list-style-type: none"> – The microphone and audio system as well as the computer and projector for power point presentations should be ready.
First thematic session;	<ul style="list-style-type: none"> – The projector + computer with power points should be ready for the head facilitator presentation. – The video to the first thematic session and microphone should be ready. – Procedure explained by head facilitator, (5 – 10 minutes). – <u>The 3 steps:</u>



	<ul style="list-style-type: none"> ○ Introduction of the theme and video presentation (15 minutes); ○ Discussions at round tables via discussion questions (50 minutes); ○ Voting (15 minutes). - During the second session the voting data should be uploaded to the web-tool.
Second thematic session;	<ul style="list-style-type: none"> - The video to the second thematic session and microphone should be ready. - The results from first session should be made ready for presentation. - The projector + computer with power points should be ready for the result presentation. - <u>The 3 steps:</u> <ul style="list-style-type: none"> ○ Introduction of the theme and video presentation (5 minutes); ○ Discussions at round tables via discussion questions (45 minutes); ○ Voting and result presentation from first session (15 minutes). - During the third session the voting data should be uploaded to the web-tool.
Third thematic session;	<ul style="list-style-type: none"> - The video to the third thematic session and microphone should be ready. - The results from second session should be made ready for presentation. - The projector + computer with power points should be ready for the result presentation. - <u>The 3 steps:</u> <ul style="list-style-type: none"> ○ Introduction of the theme and video presentation (5 minutes); ○ Discussions at round tables via discussion questions (45 minutes); ○ Voting and result presentation from second session (15 minutes). - A portable microphone for the exercise instructor should be ready. - <i>Exercise:</i> Halfway through the sessions (the day) there should be 10 minutes of physical exercise. - During the fourth session the voting data should be uploaded to the web-tool.
Fourth thematic session:	<ul style="list-style-type: none"> - The video to the fourth thematic session and microphone should be ready. - The results from third session should be made ready for presentation. - The projector + computer with power points should be ready for the result presentation. - <u>The 3 steps:</u> <ul style="list-style-type: none"> ○ Introduction of the theme and video presentation (5 minutes); ○ Discussions at round tables via discussion questions (50 minutes); ○ Voting and result presentation from third session (15 minutes).



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	<ul style="list-style-type: none"> - During the recommendation session the voting data should be uploaded to the web-tool.
Fifth thematic session:	<ul style="list-style-type: none"> - The results from fourth session should be made ready for presentation. - The projector + computer with power points should be ready for the result presentation. - During the recommendation session the voting data should be uploaded to the web-tool.
Closing remarks	<ul style="list-style-type: none"> - The screen shot from the website of the European results should be ready. - World perspective: Screen shots from the website, for transnational gathered results, should be monitored (if possible). - Information about follow-up: What will happen now, how will the results be communicated. - Explain how the participating citizens reach today's national and World results. - Practical issues (transportation etc.) - The project manager and the main facilitator give a terminal speech and thank the citizens for their participation (max 5 minutes). - Take away food (sandwiches or similar) is served. - Hard copies of the results from the thematic sessions are distributed to all citizens at the exit if possible. - Video interviews with citizens.



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EXAMPLE OF A VOTING SLIP


ID

Gender: male ☐ female ☐

Age

1. Introduction to epidemics and pandemics

1.1. To what extent did you feel familiar with epidemic and panics, before joining ASSET?

(Choose one option )

- ☐ I knew almost nothing
- ☐ I knew very little
- ☐ I knew some
- ☐ I knew a lot
- ☐ I was already an expert on the subject
- ☐ Don't know / Do not wish to answer


1.2. How familiar do you feel now?



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(Choose one option )

- ☐ I know almost nothing
- ☐ I know very little
- ☐ I know some
- ☐ I know a lot
- ☐ I am an expert on the subject
- ☐ Don't know / Do not wish to answer



Part 3: Dissemination

The purpose of this section about dissemination is to give a general overview of the dissemination activities in the project as well as to serve as guideline for the preparation and execution of a national dissemination strategy for the national partners.

GENERAL OVERVIEW

Why dissemination?

The purpose of the dissemination strategy is, first, to engage decision-makers and stakeholders in a dialogue about the project results, second, to give input to policies on epidemic and pandemics and, third, to promote the practice of citizen participation in decision-making at both the European, national and local level.

Dissemination at a national level – each partner is responsible

All partners making a citizen consultation are responsible for disseminating the results from the consultations to national policymakers and national stakeholder groups with an interest in epidemics and pandemics and/or citizen participation. The partners shall make a national *dissemination strategy* on the communication of the project and the results to political decision-makers and relevant stakeholders, including elements such as (i) personal contacts to key opinion- and policymakers and stakeholders before and after the consultation, (ii) dialogues between national policy-makers and stakeholders about the results at special events and (iii) a media strategy.

MORE SPECIFIC GUIDELINES

As mentioned above, it is the responsibility of each national partner to make sure that the relevant, national decision makers are engaged in a dialogue about of the project and its results. This requires a good national *dissemination strategy*. Each partner should prepare a first draft of their national dissemination strategy during April 2016 and send the draft to the Danish Board of Technology (jh@tekno.dk) before March 16. At the training workshop March 21-22 2016 we will discuss the dissemination strategies and share good practices. After the training workshop each partner can make further adjustments of their dissemination strategy and before June 2016 each partner is asked to send their final dissemination strategy to DBT. A template for the partner dissemination strategy is attached at page 47.

Some basic elements should be included in your strategy. The dissemination strategy should consider objectives of the dissemination, target groups, methods of dissemination, and timing.



Objectives

Keep in mind the different objectives of the project, and how these objectives relate to different target groups. Which objectives do you have with the dissemination to policy makers or NGOs, e.g. raising awareness on the project, informing of the results, engaging people in the debate, providing input to policymaking, initiate action. And what dissemination method is best suited for your objective/target group.

Target Groups

A central part of making the dissemination strategy is to identify the target groups relevant to the project. The national dissemination strategy should at least include following overall target groups:

- Key political decision-makers, e.g. parliamentary committees and Members of Parliament from your country;
- Stakeholders and NGO's;
- The media, e.g. news agencies, newspapers, radio stations, and science journals.

In order to elaborate the target groups further you should make a *stakeholder analysis*, where you identify organisations and individuals that could have an interest in the project or in epidemics and pandemics, and assess their relevance for the project. It is also an option to make a *network analysis*, where you examine the decision-making process and policy context on epidemics and pandemics by identifying how policy makers and stakeholders interact and influence each other.

With the network analysis you map formal and informal relationships among individuals and organizations and see who is important to secure effective communication about the results of the citizen consultations. This way you can identify routes of influence and key targets, and be more strategic in your dissemination by focusing on fewer important and influential actors, who has a greater influence in the network.

Dissemination methods

The dissemination strategy should also include how you will reach the different target groups, e.g. which dissemination methods are appropriate for the different target groups, and which mechanisms can you use to reach your target groups? Which initiatives are relevant and realistic for you to carry out on a regional and national level? Methods could be:

- Sending them official letters
- Arranging face-to-face meeting
- Having a high profile person open or close the citizen consultation
- Presentations for relevant committees in the parliament or regional parliaments
- Present the project on your organisation's homepage



- Ask the citizens to tell their local politicians about the project
- Blog or tweet about the project
- Initiate debates about the results with target groups
- Hold event where the results are presented and debated
- Send out press releases
- Make conference presentations
- Collaborate with national or local media
- Get trustworthy, authentic and prominent stakeholders or policymakers to become “ambassadors” for the consultations (e.g. publicly known scientists, actor/actress, politician, athlete, artist, celebrities) – remember to keep it balanced

Timing

Consider when each aspect of the dissemination should occur, e.g. when is it best to disseminate to whom? And will the dissemination be on-going? Some dissemination activities should be *pre*-consultation meetings, where you tell them about the project and try to engage them in the project or it could be *post*-consultation meetings, where you present the results. It is a good idea to make the policy-makers aware of the project/citizen consultations in the earlier stages of the project, e.g. national policy-makers and stakeholders could be consulted regarding input for a national session or their transnational cooperation on the matter. Later they can be presented more directly to the results, maybe even asked to comment on them.

Knowledge sharing

Different ways of raising awareness will be developed and shared among the national partners, such as inviting a minister to receive the results at the end of your citizen consultation, arranging a subsequent meeting between a few citizens and a minister, presenting the results to relevant parliamentary committees, making policy briefs, press releases etc.

Resources

Because the resources are limited for this consultation, it will be a good idea to decide which activities are necessary, and which can be done if the resources go further. Consider which methods will be most effective to reach your main target group, and prioritise between them.



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DISSEMINATION STRATEGY FORM

Each partner is responsible for developing a dissemination strategy to make sure that opinion-makers, decision-makers and stakeholders are made aware of the project. We would like to ask you to give us a brief overview about your strategy by answering the following questions.

Contact person(s) for the dissemination strategy at your national team

Name	Email	Telephone	Role in dissemination

Do you plan to have a national session?

Yes / No

A TARGET GROUPS

Which will be the main target groups for the dissemination in your country?

National policy makers (including MPs) (please fill in)

Name	Party/organisation	Statement (YES/NO)	Photo (YES / NO)	Reason for advocacy	Media interest documented (YES/NO)

National stakeholders and NGOs (please fill in)

Name	Profession/title	organisation	statement (YES/NO)	photo (YES / NO)	media interest documented (YES/NO)



Other key opinion makers (please fill in)

Name	Profession/title	organisation	statement (YES/NO)	photo (YES / NO)	media interest documented (YES/NO)

Media (please fill in)

Name of contact	Type of Medium (e.g. news agency, newspaper, magazine, TV, radio, online)	coverage (e.g. national, regional, local)	degree of interest in ASSET activities (low, medium, high)	special interests documen ted

Social Media

Are platforms like Facebook/Twitter/LinkedIn explored and established?

Yes / No**B DISSEMINATION APPROACH**



How, when and to whom will you disseminate the project before the consultation?	
Why have you chosen this approach?	
How, when and to whom will you disseminate the project/the results after the consultation?	
Why have you chosen this approach?	
What is your strategy for getting media attention?	
What are your criteria of success?	



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PRE-DEFINED QUESTIONS FOR CITIZENS

QUESTIONS

ASSET citizen consultations 2016

Epidemic Preparedness and Response

The questions and themes have been developed based on a number of inclusive and participatory inputs:

1. WP2 (deliverables 2.1-2.7)
2. An inter-organizational workshop in November 2015 with consortium partners
3. Input from the ASSET high-level policy forum (January 15th 2016) WP6 (T6.1)
4. Input from consortium partners on project intranet
5. Scoping online public discussion using Digital Methods

1. Personal freedom and public health safety

This theme addresses the inevitable conflict between public health safety and personal freedom and how citizens attach importance to each concern.

- Should public health authorities make flu vaccination mandatory in case of a pandemic or epidemic risk?
 - a. Yes
 - b. No.
 - c. Don't know.
- Should public health authorities make flu vaccination mandatory for health care workers in case of a pandemic or epidemic risk?
 - a. Yes.
 - b. No.
 - c. Don't know.
- What do you think is the main reason that vaccine covers of pregnant women tend to lag behind the general population?
 - a. Lack of available information
 - b. Perceived uncertainty of risks
 - c. Other
 - d. Don't know
 - e. Don't wish to answer



- Is it ok to close public services (e.g. kindergartens, offices and schools) during a pandemic/epidemic outbreak?
 - a. Yes.
 - b. No.
 - c. Don't know.

- Should authorities cancel large international events, like the Olympics, during an outbreak of an epidemic or a pandemic?
 - a. Yes.
 - b. No.
 - c. Don't know.

- What should be the principle of distribution of scarce resources (e.g. medicine) during an epidemic/pandemic outbreak?
 - a. Priority should be given to health care workers and other people working in the fields important for the society (police, army, firemen etc.)
 - b. Priority should be given to high-risk groups
 - c. Non-discriminatory, meaning first come, first served
 - d. Don't know.

2. Communication between citizens and public health authorities

This theme addresses risk and crisis communication channels and conflicts which is an integral part of any public health emergency response as a dynamic process of sharing and responding to information about a public health threat.

- Are you satisfied with the information from public health authorities during epidemic threats like Zika?
 - Yes.
 - No.
 - Don't know.

- During a pandemic or epidemic outbreak, what kind of communication channels would you prefer public authorities to use?
 - Radio
 - Social media
 - State media
 - Television
 - Official state webpages
 - None of the above.
 - Don't know.



- What is the most important information about a pandemic that you need from the public health authorities?
 - What to do/not to do
 - Routes of transmission
 - At-risk population
 - Number of cases and deaths
 - Where it is possible to take medicine/vaccines
 - Don't know
- Should public health authorities devote more resources to collect information (questions, opinions, worries, etc.) from citizens during pandemics threats?
 - Yes.
 - No.
 - Don't know.

3. Transparency in public health

Within this theme, we will ask the citizens to reflect on need for transparency in public health policymaking and the need for public health authorities to work effectively during an outbreak.

- During a pandemic outbreak like the 2009-2010 influenza pandemic, are you comfortable with certain information not being publically available for security purposes?
 - Yes
 - No
 - Don't know
- Should dialogue processes like ASSET be arranged in the future work with pandemic and epidemics response and preparedness?
 - Yes
 - No
 - Don't know
- Do you think that all relationship with vaccine manufacturer should be declared and publicly available?
 - Yes
 - No
 - Don't know
- During epidemic outbreaks like the Ebola virus disease, how should public health authorities work with new epidemic drugs and vaccines?
 - Follow the thorough established guidelines and procedures
 - Priority fast-track trail of most promising treatments and vaccines
 - Allow patient to receive treatment with an experimental drug



- Don't know

4. Access to knowledge

This last closed theme addresses various sources to acquire knowledge and ask into how to deal with the frontiers of research in public health communication.

- Do you think scientific studies in the field should be published and promoted if there is a large degree of uncertainty about the results?
 - Yes
 - No
 - Don't know
- When you are ill who do you consult first?
 - The Internet
 - Relatives
 - My general practitioner
 - Others
 - Don't know

- How much do you trust each of the following sources of information regarding the recent Zika epidemic?

	Completely trust	Mostly trust	Don't know	Mostly distrust	Completely distrust
General practitioner					
European health authorities					
National Health Authorities					
TV					
Radio					
Newspapers					
The Internet					
Friends/relatives					

- What is the best way to provide information in times of pandemics/epidemics?
 - Clear one-way communication from public health authorities
 - Dialogue through general practitioner
 - Dialogue through other platforms such as social media
 - Don't know



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5. Open session

In this session we would like you to answer the following question:

Considering the issues debated today, what is your most important recommendation to national and international policy-makers?

For this last question, question 5, what we would like you to do is, after answering the question, encircle the 2-5 most central words in your answer. By central we mean words that denote what your answer is relating to, some central actors and the main focus moving forward. Below is an example on how that could look:

In a crisis situation such as a pandemic I think the government should improve their communication to the citizens to make sure everybody knows what is going on in a given situation and how they should handle it.

Marking these 3 words highlights the main proposal in this answer. The reason we would like you to this is that this is a great way of preparing the data for further analysis.



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ENGLISH VERSION INFORMATION BOOKLET FOR PRE-MEETING INFORMATION

ASSET Citizen Consultations

On Epidemic and Pandemic Preparedness and Response



ASSET

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Glossary

Epidemic: An epidemic is the rapid spread of infectious disease to a large number of people in a given population within a short period of time, usually two weeks or less.

European Centre for Disease Prevention and Control: An independent agency of the European Union whose mission is to strengthen Europe's defences against infectious diseases. It was established in 2004 and is located in Solna, Sweden.

Fundamental rights: A term used to describe human rights as they are recognized in EU law

H1N1 (Swine flu) pandemic: The H1N1 flu virus caused a world-wide pandemic in 2009. It is now a human seasonal flu virus that also circulates in pigs.

HPV: Human papillomavirus (HPV) is a virus that causes cervical cancer and genital warts.

MMR: Measles, mumps, and rubella.

Pandemic: The worldwide spread of a new disease. An influenza pandemic occurs when a new influenza virus emerges and spreads around the world, and most people do not have immunity.

Personal freedom: Personal guarantees and freedoms of individuals that governments must respect. The scope of the term differs between countries, but often includes the freedom of press, freedom of religion, freedom of expression, freedom of assembly, the right to security and liberty, freedom of speech, the right to privacy and the right to equal treatment under the law.

Preparedness measures: Preventive measures taken to control communicable diseases and prevent epidemics.

Response measures: Measures taken during an epidemic or pandemic to respond to an outbreak.

Risk Communication: The dynamic, interactive process of sharing information strategically and effectively about an issue of high concern to help people cope, make informed decisions, and understand sensitive issues before, during, and after emergencies.

Twitter: An online social networking service that enables users to send and read short 140-character messages called "tweets". Registered users can read and post tweets, but those who are unregistered can only read them.

Vaccination: The introduction into humans of microorganisms that have previously been treated to make them harmless for the purpose of inducing the development of immunity



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Introduction

The Europe-wide citizen consultations in the ASSET project

In September 2016, ASSET will host citizen consultations in eight countries across Europe (Bulgaria, Denmark, France, Ireland, Italy, Norway, Romania and Switzerland). The aim of the ASSET Citizen Consultations is to understand how European citizens think about epidemic and pandemic preparedness and response. When you read this, it means you have been selected to participate in the citizen consultations in your country.

After the eight citizen consultations, we will write up a report with your recommendations for how to develop policy epidemic and pandemic preparedness and response in the EU. We will present the recommendations from the reports directly to relevant EU policymakers. The ASSET citizen consultations are set up to provide you with an opportunity to reflect on issues related to epidemic and pandemic preparedness and response measures, and for you to give your recommendations to how policy-makers and organisations can do better.

ASSET

ASSET is a four-year European research project. The project combines experts with many different background, e.g. public health, vaccine and epidemiological research, social and political sciences, law and ethics, gender studies, science communication and media. The aim of the project is, to develop an integrated, transdisciplinary strategy to preparedness measures.

For further information: <http://www.asset-scienceinsociety.eu/>

About this booklet

This information booklet is written to provide you with background information on the themes that will be discussed during the ASSET citizen consultations. Once you are at the meeting you will be asked to vote on questions related to each topic. The questions and the information material is the same at all eight citizen consultations. Following the meetings, we can then compare the results to see similarities and differences among countries.

In this booklet you will find an introduction to four themes all relevant to epidemic and pandemic preparedness and response. The content mainly builds on previous information reports made by experts in the ASSET project (these reports can be found on the ASSET webpage). In addition to these reports, we have analysed Twitter to find out what themes are discussed online. We have focused on discussions raised by non-scientific experts on topics related to epidemics and pandemics. In this booklet, we have highlighted some of the discussions we found on Twitter. Every time a Twitter story is described in the booklet, you will find a little Twitter icon as to the left.





Balancing individual rights and the common good in the event of epidemics or pandemics

Introduction

In this chapter, we provide an overview and discuss relevant ethical and fundamental rights considerations in situations of public health emergencies, such as epidemics and pandemics. There is a saying that goes, “extraordinary circumstances require extraordinary measures”. In times of crisis, pandemic planners and policy makers are challenged to balance extraordinary measures with respect for fundamental human rights and ethical tensions that can arise at different phases of a pandemic.

Preparedness measures

During an epidemic or pandemic threat public health authorities can use a number different preparedness measure, some of which entails certain restrictions on personal freedoms.

Vaccination

Despite the advances in medical illness treatment, prevention is still the most effective remedy. In times of epidemic threats, isolation, vaccination and quarantine is still the dominant epidemic response. Since the H1N1 pandemic vaccination rates on seasonal flu and other vaccines, including polio and measles has declined. This has spawned a debate of mandatory vaccinations. The proponents say this would help to eradicate diseases and should be regarded as a common good for society. Opponents, on the other hand, view vaccination as a personal choice, and points to the conflict between fundamental rights (the autonomy of persons to make decisions), and mandatory vaccination. Some also argue that some people have a greater responsibility to vaccinate than others. This includes health care workers. Being exposed to infectious diseases on a daily basis, health care workers risk getting ill themselves or pass on the infection to other patients, some with a reduced immune system. Studies have generally shown compliance rates from as low as 10% to 40-50% among health care workers, with no clear pattern to ascertain why this is.

How vaccines were discovered:

Vaccines aim to enable the body to fight a particular infection. In 1796 the Englishman Edward Jenner injected an eight-year-old boy with smallpox. At the time one of the deadliest diseases in Europe, yet no disease developed. Jenner has observed that milkmaids almost never contracted the disease. As he would come to learn, the far less deadly cowpox proved an effective immunization against smallpox. Prior to injecting the boy with smallpox he had injected him with cowpox, which proved his hypothesis. Doctors across the world has adopted this technique, and developed it to the most effective means to fight and eradicate infectious diseases since, including smallpox.

Women who are pregnant are more likely to have severe disease and hospitalisation with influenza, and during pandemics, the mortality rate for pregnant women is higher than non-pregnant women.

There are a number of reasons why pregnant women are more at risk of influenza. Hormonal changes during pregnancy, the increased demands on the heart and the dampening of the woman's immune system



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to prevent rejection of the foetus, all make the strong antiviral response that is needed to control a viral infection more difficult.

The WHO recommends all pregnant women to receive vaccinations during the influenza season, and that they should be given highest priority among all the risk groups. However, influenza vaccine covers of pregnant women tend to lag behind the general population.

This is due partly to pregnant women not knowing about the increased risk; also, many health care providers do not recommend pregnant women to take a pandemic or seasonal influenza vaccine due to concerns over giving a vaccine to a pregnant woman, despite the influenza vaccine being safe for pregnant women.

In this context it is interesting that a recent ASSET study points to mandatory vaccination has limited effects on coverage. The study found no evidence of a relationship between mandatory vaccinations and rates of childhood immunization in European countries.

Despite vaccinations' central role in epidemic preparedness, some people have raised concerns about the practice. They have linked several vaccines to serious side effects. The MMR vaccine has by some groups been linked to cause autism, though this has no scientific backing.



Other preparedness measures

The restriction of personal freedoms in response-phase of a pandemic is an intervention, which aims to control the spread of the disease. It, can take several forms e.g. quarantine, isolation, border control and social-distancing measures.

Quarantine: The restriction of the movement and activities of healthy persons or animals that have been exposed to a suspected or confirmed case of communicable disease during its period of communicability (i.e., contacts) to prevent disease transmission during the incubation period if infection should occur.

Isolation: Separation, for the period of communicability, of infected persons or animals from others under such conditions as to prevent or limit the transmission of the infectious agent from those infected to those who are susceptible or who may spread the agent to others.

Border controls: Measures that are designed to limit/control spread of infection across entry points to the country. They can include travel restrictions, entry or exit screening, reporting, health alert notices, collection and dissemination of passenger information, travel advisories or restrictions, etc.

Social distancing: A range of community-based measures to reduce contact between people (e.g. closing schools or prohibiting large gatherings). Community-based measures may also be complemented by adoption of individual behaviours to increase the distance between people in daily life at the work site or in other cautions (e.g. substituting phone calls for face-to-face meetings, avoiding shaking hands).

Individual rights vs the common good

All of the preventative measures described in the above section is applied to individuals or entire communities. The measures are often applied even though authorities might lack conclusive evidence about the nature of the epidemic threat. Consequently, there is considerable potential for ethical issues to arise.

The question is, when restrictions on personal freedom are justified? In broad terms, legitimate restrictions on personal freedoms may occur if, in exercising one's freedom, one places others at risk. It is perhaps isolation and quarantines the two situations, which have the most serious ethical implications as they directly impose restrictions on personal freedoms and challenge fundamental rights for citizens. Quarantine and isolation cause a tension between the interests of society in protecting and promoting the health of its citizens, and the interests of individuals in civil liberties such as privacy, non-discrimination, freedom of movement, and freedom of arbitrary detention.

Nonetheless, coercive public health measures such as isolation and quarantine can be legitimate when justified when balancing the public health interests of society against the freedom of the individual.

Twitter story



In May 2016 a group of scientists united to urge WHO and the International Olympic Committee to move or postpone the 2016 Rio Olympics. The experts argued that new findings about Zika made it unethical for the



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Games to go ahead. The discussion quickly spread on Twitter, and people commented on the story by using hashtags such as #MoveOlympics and #Zika.

An example of such an online public discussion is the 2016 Rio Olympics. Following the 2015-2016 Zika virus epidemic fractions within science, ordinary citizens and the media has brought attention to the outbreak. In May 2016 a group of scientist united to urge WHO and the Olympic committee to move or postpone the games.



Twitter story 1: A frequently retweeted news story of health experts urging the Rio 2016 Olympics to be moved or postponed.

Since more than 100 health experts from across the globe urged WHO to exert pressure on the International Olympic Committee and the Brazilian government to consider moving the Olympic Games, thousands of Twitter users have engaged in the discussion. Often they have either expressed concern for going on with the Games, or their support for going on as planned. WHO refused to endorse the warning and the 2016 Rio Olympics was declared open on August 5th, 2016.

Prioritizations and allocation of scarce resources

Any public health emergency of pandemic scale requires from governments to make difficult decisions regarding prioritizations and allocation of scarce resources, which include both human and material resources. What is characteristic of any pandemic event, is the fact that an extraordinary high number of people over a large geographic area will require care at the *same time*, with an immediate impact on the availability of both human and material resources.

Some of important questions to be considered by public health authorities in their distribution plans include:

- What scarce goods are involved in the distribution plan?



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- Who will decide about prioritization and distribution?
- Who is eligible to be a recipient?
- What morally relevant criteria will be employed for priority-setting?

In deciding upon such questions governments and public health authorities often apply the principle of equity. This means practices that are considered fair, but not necessarily equal. This could be prioritizing the treatment some groups before other. For example, the WHO recommends giving priority to vaccinating health care workers, as they have a role to fulfil during a pandemic for the benefit of society.

Summary

In this chapter we have introduced different preparedness measures, discussed pros and cons of their application, particularly the tension between individual rights and the common goods. At the citizen consultations we invite you to discuss how we should balance individual rights and the common good in the event of epidemics or pandemics.



Communication between citizens and public health authorities

Introduction

This theme addresses risk communication channels and conflicts, which part of any public health emergency response. It is a dynamic process of sharing and responding to information about a public health threat, like an influenza pandemic or an Ebola outbreak.

Risk communication is the health care authorities' go-to tool to control irrational fear and rumours-based behaviour in the public. The general aim is limiting morbidity and mortality and even economic losses caused by the disease. According to the European Centre for Disease Prevention and Control the ideal form of risk communication during an epidemic threat "maximizes the public's capacity to act as an effective partner by encouraging prevention, promoting containment, fostering resilience and recovery".

How do public health authorities communicate?

Communication strategies

Risk communication broadly aims at improving collective and individual decision making and cover preparedness, response and recovery. Risk communication predominantly focuses on preparedness and analysing the conditions needed for the public to acquire information, skills and participatory opportunities when no imminent threat is apparent. During an outbreak risk communication focuses on the response.

Such response communication could include messages about:

- Spread and lethality
- Action recommendations
- Social media stories

Generally, public health authorities aim at making risk communication simple, with clear messages tailored to the target-group they want to reach.

Information channels

Communicating about relevant threats and including the public in the process is very important. However, health authorities also need to decide which media and information channel they will use. There are many types of media and information channels in which risk communicators can broadcast information, for instance at public meetings, newspaper, radio, television, or the Internet – many of which often are applied in a combination.

In making this choice, risk communicators are faced with two central considerations they have to reflect on: the trustworthiness and reach of the medium.

Regarding trustworthiness, it is important to realize that all sources are not equal. Many factors affect individual choice, such as gender, age and education. Still, a study aggregating the publics' perceived trustworthiness of different media suggested the following relative ranking:



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1. Family Doctor
2. University researcher
3. Media
4. Local government
5. Federal government
6. Industry



Photo 1: Citizens in general consider family doctors the trustworthy source for public health information

Concerning the reach of the different information channels, it does not suffice to spread the message as wide as possible, as certain groups cannot be reached through particular information channels. For instance, elderly people and social media communication channels are a bad match. Table 1 summarises what target groups match which information channels.

Information channel	General public	Elected officials, policymakers and activists	Immigrants and refugees	Elderly	Families with children	Homeless
Website	✓	✓			✓	
Email list		✓				
Social media	✓	✓			✓	
Community meetings	✓			✓	✓	
Flyers	✓		✓	✓	✓	✓
Community-based groups			✓	✓	✓	✓
Faith-based groups			✓	✓	✓	✓
Schools and child care	✓		✓		✓	
Health care providers			✓	✓	✓	

Table 1: Match between information channel and target group.

Following the table above, risk communicators closely consider which information channel they use, when they consider the reach. For example while mass communication might reach more people, more direct communication is needed for reaching immigrants, e.g. through health care workers.

Challenges

Risk communication during pandemics is particularly challenging. The challenge comes from pandemics spreading over larger geographical areas requiring coordination among countries, and the fact that pandemics have a longer time scale than epidemics. A central recommendation from an expert group following the H1N1 pandemic, was a call for more and better two-way communications between science and society. In particular, the decreasing level of trust in public authorities and emergence of rumours were highlighted as central challenges.



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Dialogue to avoid the spreading of rumours

In the case of the recent Ebola epidemic many rumours have flourished. Amongst the most popular was that Western health workers spread the disease, based on American imperialistic visions. This problem manifested itself into locals hiding sick or dead people. Such rumours constitute parallel information systems. The 'trust crisis' and lack of confidence in scientific expertise following the H1N1 pandemic changed the attitudes of many families regarding vaccination, contributing to reduced immunization rates in some areas, leaving clusters of children unprotected, i.e. against polio, and preventing the achievement of important goals, such as measles eradication from Europe.

Many experts say a genuine two-way communication strategy would largely lessen these challenges of risk communication. An alternative communication means towards this is social media communication. Below we will give an example from Twitter.



Twitter story

Consistency of information is essential in risk communication as people become confused and concerned when exposed to different and sometimes conflicting risk messages. That is why authorities are very often inclined to withhold information until they are absolutely sure that the message is true — and to reconcile the message within the authorities before communicating to the public.

An example, is the time lack between Zika being declared a global health emergency by the World Health Organization (WHO), and the public discussion of the virus. So while the public had discussed Zika for months, the WHO waited until February 2016 to go public with their declaration in order to focus their risk communication first.



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Twitter story 2: Margaret Chan, the Director-General of WHO declared Zika a global health emergency at a press conference in February 2016.

When the WHO in February this year declared Zika a global health emergency, due the rapid spread of the Zika virus, it was only the 4th time the WHO have declared a such state since its inception in 2007, the three previous instances were H1N1, Ebola and Polio. While Twitter user had been discussing the virus prior to this event, the number of tweet many doubled as a reaction to WHO's declaration.

Summary

Above we have introduced the what, why and how of risk communication, discussing which information to communicate and how to do it. During the citizen consultations, we invite you, among other issues, to discuss which information channels you trust and would like the health authorities to communicate through.



Transparency in crisis situations

In this chapter we ask you to reflect on tension between transparency and secrecy in public health and if there is a role for citizen participation during a crisis. Related to the transparency discussion we will furthermore like you discuss the conflict of interests that exist within public health governance.

Tension between secrecy and transparency

The tension between secrecy and transparency is a fundamental dilemma. As too much transparency might leave states vulnerable the risk of intentionally caused outbreaks (i.e. bioterrorism), too much secrecy might diminish public trust and jeopardize effective risk communication. For example, if a state suspects an intentional outbreak, the government may hold information back from on public communicative to work effectively. However, public communication is essential to keep the publics' trust, as discussed in the previous chapter.

Citizen Participation

Policy-makers often decide on which level they will protect citizens, with only basic knowledge of what the citizens actually require. For example, citizen participation is very rarely reported in the national epidemic preparedness plans. It is a problem for governance taking into account that the experts' opinion may differ from the public opinion in many cases. With obvious normative elements, involving a lot of the conflicts and dilemmas we describe in this booklet, pandemic and epidemic governance is well-suited for citizen participation. Arguably, since the citizens are the ones that are going to live with the consequences, it is only fair that they should have a voice in the preparedness planning.



Twitter story

An example of the divergence between authorities and the public is found in a Twitter story from Venezuela.

While the Zika virus epidemic ripped through Latin America in February 2016, many states came out with public-service warnings about mosquitoes and publish tallies of new cases. Venezuela played down the epidemic, and restricted information about its spread. Public health experts and doctors believed that the government was significantly underreporting on the Zika virus toll, which officially stood at around 5,000 cases. Some independent experts estimated that there might have been more than half a million cases of the mosquito-borne disease. This number would place Venezuela the second-most effected country, only surpassed by Brazil.



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macloco @macloco · 16. feb.

#Venezuela faces 'worst-case #scenario' as #Zika #outbreak expands -
#SOSVenezuela



Venezuela faces 'worst-case scenario' as Zika outbreak expands

Hospitals lack basic medications and birth control is scarce as the country reels from an economic crisis.

washingtonpost.com



Twitter story 3: Twitter users in Venezuela tweeted stories, like this [Washington Post](#) article, during the Zika epidemic.

Venezuelan Twitter users used the medium to share news stories and personal testaments of the Zika virus. In this way two different stories of the situation in Venezuela spread online. While it is hard to know the reasons behind the official government position on Zika in Venezuela, the Twitter stories show a gap between the perspective of the public and the government on the seriousness of the situation. This led infectious-disease specialists to using social networks to try to understand the scope of the Zika outbreak.

Conflict of interest

The legacy the 2009 H1N1 pandemic, is often discussed in the context of conflict of interest in the health care industry. As a consequence, people started to think of pandemics as less dangerous. Peoples' perception of the risk of many others infectious diseases also seems to have changed as a result. Many people in Europe and USA believe that WHO overreacted during the H1N1 Pandemic. They believe that the overreaction was due to the WHO's ties with the pharmaceutical industry. In their mind, influenza is a trivial disease, and pandemic flu is not a serious threat. The loss of confidence in international and national health authorities also had a strong impact on seasonal influenza vaccinations. In addition mistrust of vaccinations in general grew as well , (for example regarding the measles and polio vaccines).

The World Health Organization, receives limited financing, and therefore relies upon voluntary contributions. Part of such voluntary contributions stem from major pharmaceutical companies. In addition, the scientists who advised the World Health Organization on its influenza policies and recommendations—including the decision to proclaim the so-called swine flu a "pandemic" had close ties



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to companies that manufacture vaccines and antiviral medicines like Tamiflu. The WHO did not publically disclose this fact.

The use of experimental drugs in crisis

During an epidemic or pandemic outbreak people become anxious. Anxiety and fear puts pressure on authorities to try out experimental drugs or vaccines. This could include fast track of experimental drugs. An experimental drug is a medicinal product (a drug or vaccine) that has not yet received approval from governmental regulatory authorities for routine use in human or veterinary medicine. A medicinal product may be approved for use in one disease or condition but still be considered experimental for other diseases or conditions.

During the Ebola epidemic scientists tried out a variety of experimental drugs. Experimentation took place under the pressure to a drug to treat, or a vaccination to stop or slow the spread of the virus. While the processes for approval of medical drugs are very detailed, some argue that during an epidemic or pandemic threat they should be lessened. Arguing that we morally owe desperate ill and dying people to try interventions that might help them, including experimental drugs.

Summary

We have discussed how secrecy and transparency sometimes can be viewed as a trade-off. We also introduced the role of citizen participation during crisis or an epidemic or pandemic threat. At the citizen consultations you will be discussing to which extents it is okay for public authorities keep information from citizen and how to deal with conflicts of interest.



Trust, Action and Access to Knowledge

Finally, we would like to explore the issues of trust and behaviour. In the previous chapters we already talked about the dilemmas faced by public health authorities in choosing what, how and when to communicate about risks, and collaborations with pharmaceutical companies and businesses. In this section we discuss the relationship between trust in organisations and media, and people's behaviour.

The relationship between trust and action

Building trust and credibility source is fundamental challenge for public health authorities and international health organisations. Indeed, in absence of trust communication about risk and preferred behaviour can be ignored. When trust is high recommendations on for example behavioural change, are more widely and coherently followed. This is particularly true during an epidemic or pandemic threat, as people under distress are known to become emotional and distrustful.

It is interesting to note that international organizations may be perceived as more trustable than National Health authorities, because the latter are perceived as political organization acting more following political interests than for the benefit of the general public. This is a very serious issue since public trust in authorities is a crucial factor in effective risk communication.

In particular, during the H1N1 pandemics public authorities had to face recurrent rumours in the traditional media and on the Internet on conspiracy between them and pharmaceutical industries, leading to allegations that H1N1 was a "fake epidemics". Therefore, part of the risk communication during H1N1 pandemics showed communication failures. During and especially after the H1N1 pandemic this resulted in a wave of lack of trust in governments and agencies and other agencies that propagated in EU public undermining future risk communication.

Communication of uncertainty

A related dilemma to trust and action is how to communicate uncertainty. An ideal risk communication model is difficult to apply during an epidemic or pandemics outbreak, where the quantification of risk is uncertain and subject to updates as long as data accumulates. However, it is proven that it is important to get information out to the public as early as possible, even if it is just to say that you are investigating the situation and will provide updates, will help deflect rumours and misinformation. However, public health authorities must balance speed with accuracy, as misinformation might reduce trust and credibility as discussed above.

Still, trust in the authorities in charge of risk communication is crucial. Australia provides an example on how uncertainty was managed in the context of risk communication during the H1N1 pandemics. By acknowledging uncertainties together with reassuring of government preparedness, they have been praised to their communication of uncertainty. At the other end of the scale has Venezuela been highlighted as a worst-case handling of uncertainty – explained in Twitter story 3.

The role of the internet and social media in influencing behaviour

Risk and crisis communicators face pressure to adapt to the changing 21st-century landscape. With threats of intentionally caused outbreak (i.e. Bioterrorism) and other new threats constantly emerging, it is



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essential to understand how social media (e.g., WhatsApp, Facebook, Twitter and more) are shaping communication during an outbreak.

Many actors did for long not exploit the opportunities coming with social media. For instance was public engagement was largely missing when the New Orleans levees broke after Hurricane Katrina made landfall in August 2005. In today's environment, however, lack of awareness is no longer an issue. Citizens not only consume information from multiple sources, they provide it as well. For example, during the current Zika virus epidemic international health authorities has exploited citizens reports of outbreak in Latin America.

Social media also affects behaviour. Public opinion is not solely built from institutional messages, but also includes shared testimonies, advices, discussions with family, friends, neighbours, family doctor, and professionals, as well as TV, newspapers, the Internet (databases, Google, participative spaces, that is, forums, Facebook, Twitter and WhatsApp). However, it is also important to stress that, even though the Internet and social media are widely considered as new information sources, many actors do not use them.



Twitter story

A feature of social media is that political issues travels between different discussions. For example, in February 2016 Pope Francis announced that contraception may be used in the fight against the Zika virus. On Twitter, Pope Francis' statement was used as a wedge to open a debate on women rights and abortion connected to discussions on Zika.



TRUNews™ @TRUNews · Feb 9

"I Have **#Microcephaly**. We Need Treatment, Not **#Abortion**"
tru.news/1Q5FggO **#zika** **#prolife**



"I have **#microcephaly**" is a story being used to drive anti-abortion statements. The article being shared and retweeted by a number of users and organizations is a story about a young woman who suffers from microcephaly. The main argument is that microcephaly is not dangerous,

Twitter story 4: An anti-abortion tweet following Pope Francis statement on contraception in the fight against the Zika virus.

but just needs more medical attention, and thus is not a reason for abortion. Anti-abortion groups tend to use **#prolife** to drive an anti-abortion statements, but counter arguments also use the same **#prolife**, to drive pro-abortion statements.

Summary

In this final chapter we have discussed the role of social media in risk communication and how authorities should deal with communication of uncertainty, highlighting how it worked in Australia and how Venezuela have struggled. This will be focal point of the discussion at the citizen consultation as well.



Key points

- When balancing individual rights and the common good in the event of epidemics or pandemics a central question is, when restrictions on personal freedom are justified? In broad terms, legitimate restrictions on personal freedoms may occur if, in exercising one's freedom, one places others at risk.
- Communicating about relevant threats and including the public in the process is very important. There are many types of media and information channels in which risk communicators can broadcast information, for instance at public meetings, newspaper, radio, television, or the Internet – many of which often are applied in a combination. However, not all media match all target groups.
- The tension between secrecy and transparency is a fundamental dilemma. As too much transparency might leave states vulnerable the risk of intentionally caused outbreaks (i.e. bioterrorism), too much secrecy might diminish public trust and jeopardize effective risk communication. For example, if a state suspects an intentional outbreak, the government may hold information back from on public communicative to work effectively. However, public communication is essential to keep the publics' trust, as discussed in the previous chapter.
- Risk and crisis communicators face pressure to adapt to the changing 21st-century landscape. Citizens not only consume information from multiple sources, they provide it as well. For example, during the current Zika virus epidemic international health authorities has exploited citizens reports of outbreak in Latin America.



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List of literature

This booklet has been based on reports from the ASSET project, in particular the following reports, which can be downloaded from: <http://www.asset-scienceinsociety.eu/outputs/deliverables>

- D2.1 - Governance Report
- D2.2 - Reference Guide on Scientific Questions
- D2.3 - Crisis Participatory Governance Report
- D2.4 - Ethics, Law and Fundamental Rights Report
- D2.5 - Report on Gender Issues
- D2.6 - Report on Intentionally Caused Outbreaks
- D2.7 - Transdisciplinary Workshop Report

Further following websites have used in the preparation:

<http://www.asset-scienceinsociety.eu/>

https://ec.europa.eu/research/swafs/pdf/pub_archive/sis-heg-final-report_en.pdf

<https://twitter.com/>

<http://www.who.int/en/>



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ENGLISH VERSION INFORMATION VIDEOS FOR THEMATIC INTROS TO MEETING SESSIONS

1. PERSONAL FREEDOM AND PUBLIC HEALTH SAFETY/MANUS

Speak english	Translation
<p>Titel:</p> <p>Personal Freedom and Public Health Safety</p> <p>8 sec.</p>	<p>Animated microscope pictures of viruses</p>
<p>TC: 00.08.00</p> <p>Pandemics are feared because of the possible disastrous consequences. Diseases like Ebola, Zika and different forms of flu are infectious and spread easily, but that doesn't mean they are pandemic.</p>	
<p>TC: 00.23.00</p> <p>A pandemic is defined as an infectious disease that can easily and quickly spread among people over very large geographic areas. A pandemic - at least in its extreme - hits people across the globe.</p>	
<p>TC: 00.43.00</p> <p>Pandemics have been known for centuries. The Black Death or Bubonic Plague that killed 60% of the European population in the 14th century.</p> <p>And the influenza pandemic of 1918-1919 known as "Spanish Flu" was a global disaster that killed between 20 and 40 million people. Therefore scientists have been preoccupied with finding a way</p>	



to prevent the epidemic diseases.	
<p>TC: 01.14.09</p> <p>Vaccination was invented in 1796 by the English doctor Edward Jenner. He developed the vaccine against smallpox, by injecting humans with weakened versions of the smallpox virus.</p>	
<p>TC: 01.30.00</p> <p>Since Jenner's discovery, many more vaccines have been developed, and have become our most effective means of fighting infectious diseases.</p>	
<p>TC: 01.42.00</p> <p>But all vaccines have side effects. For instance the HPV vaccine against cervical cancer can cause headaches and nausea, but scientists have not found any serious side effects.</p>	
<p>TC: 01.55.00</p> <p>Still some parents will not let their daughters have a HPV vaccine, because they are afraid of serious side effects like cancer and permanent headaches. Rumours about serious side-effects spread quickly on for instance social media and is one among many examples of the conflicts between scientists and patients' experiences of vaccines and their side effects.</p>	



<p>TC: 02.23.00</p> <p>Another question is: how effective is the vaccine? A vaccine against flu is only effective against a small spectrum of possible variations, and the flu virus is mutating very quickly. This means that a general flu vaccination only provides limited protection.</p>	
<p>TC: 02.41.00</p> <p>Effectiveness is also a question about how many individuals in a population are vaccinated. If someone with measles is surrounded by people who are vaccinated, the disease can't easily be passed on, and it will disappear quickly. This is called 'herd immunity' or 'community immunity', and it gives protection to vulnerable people such as new born babies and those who are too sick to be vaccinated.</p>	
<p>TC: 03.11.00</p> <p>This leads to the question of whether vaccination should be mandatory. Studies by ASSET suggest this has limited effects, but still authorities put pressure on people:</p> <p>In a sentence in a criminal court in France a couple received a two-month suspended jail sentence for not letting their children have a polio, tetanus and diphtheria vaccination.</p> <p>They didn't mind the polio vaccination, which was the only mandatory vaccination, but it was pooled with tetanus and diphtheria which they objected to.</p>	



<p>TC: 03.47.00</p> <p>One group where mandatory vaccinations are in question is health workers, since they are themselves a high risk group and also in risk of spreading viruses to groups with a weak immune system.</p> <p>But health workers are rarely vaccinated. For instance, in Ireland only 18% of nurses are vaccinated against flu, despite being a risk group, and this leads to the question whether vaccination against flu should be mandatory for health workers.</p>	
<p>TC: 04.19.00</p> <p>As we have seen mandatory vaccinations and other measures taken as a response to pandemics often interfere with people's ability to make individual choices. In some situations it is convenient to isolate infected persons or communities to prevent spreading of an infection. This was the case when Ebola spread in Liberia, Sierra Leone and Guinea in 2014.</p>	
<p>TC: 04.46.00</p> <p>Ebola has a high mortality rate, and there is no vaccination or cure. It is therefore necessary to track down and isolate patients and people who have been in contact with infected people to stop the outbreak.</p> <p>Infected patients are placed in a so-called isolation</p>	



device and staffs coming in contact with Ebola patients have to wear isolation suits.	
<p>TC: 05.46.16</p> <p>Soon after the Ebola outbreak an airline passenger from Liberia introduced the virus into Lagos in Nigeria. This incident caused stricter border controls to stop Ebola from spreading further.</p>	
<p>TC: 05.32.00</p> <p>Another strategy for fighting infectious diseases is preventing people from gathering in large groups. Authorities can choose to close down concerts or sport events, but it is not always agreed on when to do so.</p>	
<p>TC: 05.48.10</p> <p>Across the World health experts have urged the WHO to put pressure on the Olympic committee and the Brazilian government to move the 2016 Olympic games from Brazil.</p>	
<p>TC:05.59.16 Soundbit</p> <p>'The olympics ought to be postponed or moved'</p>	



<p>TC:06.04.00</p> <p>They are worried about the rapid spread of the Zika virus. The WHO disagrees and maintain that there are no public health justifications for moving the games.</p>	
<p>TC:06.18.00</p> <p>In case of pandemic emergency the WHO has made recommendations on how to distribute scarce resources based on the principle of “equity”. This means practices that are considered fair, but not necessarily equal. It might be necessary to prioritize some groups before others. For instance the WHO recommends giving priority to vaccinating health care workers, since public health care need to function during a pandemic.</p>	
<p>TC:06.53.00</p> <p>The WHO also insist on global justice. Most countries' national plans focus on protecting their own citizens, an approach which favours economically powerful countries. But according to the WHO technology and resources should be shared with developing countries.</p>	
<p>TC:07.12.00</p> <p>Equal access to information is also an issue. Everyone should have access to information from</p>	



public health authorities and governments should use a wide range of methods to reach all citizens.	
<p>TC:07.27.00</p> <p>In the case that countries face a scarcity of resources in a pandemic emergency how should governments then prioritize? Who should be prioritised? Pregnant women, the elderly, children, healthcare workers or government officials?</p>	
<p>TC: 07.47.10 Text</p> <p>What do you think?</p> <p>Enjoy the debate</p> <p>TC: 07.54.00</p>	

2. COMMUNICATION BETWEEN CITIZENS AND PUBLIC HEALTH AUTHORITIES/MANUS

Speak	Translation
<p>Title:</p> <p>Communication Between Citizens And Public Health Authorities</p>	
<p>TC: 00.07.00</p> <p>Communication is an integral part of any public health emergency response.</p>	
<p>TC: 00.13.00</p> <p>And in this process of informing the public it is important that public health authorities are able to respond to questions and worries from the citizens and to use the proper channels to</p>	



inform the public.	
<p>TC: 00.26.00</p> <p>This WHO film about the Zika virus is one example.</p>	
<p>TC: 00.26.00 Soundbite</p> <p>‘ If you are living in an infected region, you do need to take personal protection. That means making sure that mosquitoes are excluded from your house ...’</p>	
<p>TC: 00.41.18</p> <p>This is called risk communication, and the purpose of risk communication is to ensure that messages and strategies that protect citizens from threats to their health reach the public quickly and effectively.</p>	
<p>TC: 00.57.05</p> <p>In this process, interaction and exchange of information and opinions are important to help everyone understand the risks to which they are exposed and encourage them to participate in minimizing or preventing these risks.</p>	
<p>TC: 01.16.03</p> <p>When creating a plan for risk communication, there are several things to consider: The first is that the source has to be trustworthy if Authorities want the public to act according to recommendations. But public health authorities are not automatically seen as trustworthy by the public. It often happens that alternative versions of the information shared by authorities about an outbreak, disease or treatment emerge and circulate in the public.</p>	



<p>TC: 01.51.16</p> <p>In the case of the Ebola epidemic in West Africa many alternative explanations of the Ebola epidemic emerged. Amongst the most 'popular' was that Western health workers spread the disease. As a result locals hid away sick or dead people from authorities.</p>	
<p>TC: 02.11.16</p> <p>Rumors constitute parallel information systems. They can be hard for authorities to deal with, and they are often feed by misunderstandings and insufficient dialogue among authorities and local communities.</p>	
<p>TC: 02.34.11</p> <p>One way to minimize the emergence of parallel information systems, or rumors, could be to include citizens and civil society in risk communication and organize responses to epidemic and pandemic threats in such a way that rumor will not be the main information channel.</p>	
<p>TC: 02.56.18</p> <p>Broader dialogs and more openness could improve the public perception of authorities and possible increase trust among partners as well.</p>	
<p>TC: 03.08.01</p> <p>Another issue to take into account is the social group with whom authorities communicate. Audiences may be diverse, ranging from families, young people and the elderly. They might need different types of information, different types of explanations and might not be able to engage in dialogue in the same ways.</p>	
<p>TC: 03.31.20</p>	



Communicating risk can be accomplished in the media through a variety of methods, depending on the type of threat and the urgency with which the information must reach its audience.	
<p>TC: 03.45.10</p> <p>These methods include for instance: hosting news conferences and public meetings, talking to journalists.</p>	
<p>TC: 03.53.07</p> <p>Buying advertising, maintaining a dedicated website with opportunities for feedback.</p>	
<p>TC: 04.00.14</p> <p>Posting to online forums.</p>	
<p>TC: 04.03.014</p> <p>Providing experts to radio and television call-in shows.</p>	
<p>TC: 04.09.02</p> <p>Writing letters to the editor and submitting opinion pieces.</p>	
<p>TC: 04.15.19</p> <p>Effective risk communication must also be successful in identifying the cultural dimensions and priorities of the targeted groups. One of the things that should be taken into consideration in this process is the communication channels. Different groups prefer different channels.</p>	
<p>TC: 04.37.06</p> <p>Information channels are not judged as equally trustworthy. Typically, people trust their family doctor and information from researchers, above that coming from media, governmental</p>	



institutions and the medical industry.	
<p>TC: 04.54.15</p> <p>The question is: what is the best way for public health authorities to communicate their messages to the public in case of an epidemic or pandemic? Or should they use a wide range of ways to reach the public?</p> <p>TC: 05.10.10</p>	
<p>TC: 05.12.00 Text</p> <p>What do you think? Enjoy the debate</p> <p>TC: 05.19.00</p>	

3. TRANSPARENCY IN PUBLIC HEALTH/MANUS

Speak english	Translation
<p>Titel: Transparency in Public Health</p> <p>7 sec</p>	
<p>TC: 00.07.10</p> <p>One of the problems public health authorities face when informing the public is to strike a balance between secrecy and transparency.</p> <p>On the one hand authorities do not want to cause unnecessary fear or confusion; on the other hand they do not want the public to feel they are being lied to or denied access to important information.</p>	
<p>TC: 00.31.00</p> <p>Sensitive information that authorities struggle to decide on whether to disclose are for</p>	



instance information about the amount of vaccines available and knowledge about possible side-effects.	
<p>TC: 00.46.00</p> <p>Today, communication about epidemics and pandemics are mainly 'one-way' communication coming from authorities and experts. They possess all information about effectiveness of medicines and spread and severity of diseases. And they are making decisions on preparedness, response and recovery plans in case of an epidemic or pandemic outbreak.</p>	
<p>TC: 01.12.10</p> <p>But it is possible to take another approach and involve citizens. Public health authorities could communicate with the public in different ways and for instance take concerns about side effects into account, even if has not yet been established as scientific fact.</p>	
<p>TC: 01.32.00</p> <p>The vaccine against the HPV virus for young girls is one example, where girls experience side effect that are not scientifically proved.</p>	
<p>TC: 01.44.10</p> <p>Preparedness plans could be based on input from local communities about their desires and needs in an outbreak situation and they could provide authorities with specific knowledge about their community. The public could have influence on how resources like vaccines are distributed, or on when and where to take</p>	



precautions like closing schools or suspending public events.	
<p>TC: 02.11.10</p> <p>On the one hand citizens have a right to be involved in decisions that affect them and they have valuable local knowledge, which can improve the efficiency of a response to public health threats.</p> <p>On the other hand involving the public can make it more difficult for the authorities to work effectively.</p>	
<p>TC: 02.32.00</p> <p>In fighting epidemics and pandemics, there can be a conflict of interest between public health authorities and the pharmaceutical industry. Industry want to sell their products and this could lead to over emphasis on risks of a disease, and the need for a vaccine. The 2009 the H1N1 or swine flu pandemic is one example:</p>	
<p>TC: 02.57.10</p> <p>Multinational corporation's donations pay nearly 80 percent of the World Health Organisations expenses.</p>	
<p>TC: 03.04.00</p> <p>The scientists who advised WHO on to proclaim the so-called swine flu a pandemic, had close ties to companies that manufacture vaccines and antiviral medicines like Tamiflu, but this information was withheld from the public.</p>	
TC: 03.24.10	



<p>The World Health Organization handling of the swine flu influenced the general understanding of the risks in a situation with a pandemic. A German study showed that “during the peak of the swine flu only 18% of participants stated that they perceived the risk of pandemic influenza as high; this proportion fell to 10% in January 2010”.</p>	
<p>TC: 03.51.00</p> <p>The loss of confidence in health authorities had a strong impact on seasonal flu vaccination too, and it added to growing public mistrust towards other vaccinations such as measles and polio.</p>	
<p>TC: 04.07.00</p> <p>The pharmaceutical industry is also racing to develop treatments or vaccines that will stop the epidemics and scientists are tempted to offer experimental treatments to people suffering from life threatening illness like Ebola. This was the case with the American doctor Kent Brantly who caught Ebola while he was fighting the disease in Liberia. He treated himself with an experimental drug, which was years from getting an approval from American health authorities, and he recovered.</p>	
<p>TC: 04.24.00</p> <p>This was the case with the American doctor Kent Brantly who caught Ebola while he was fighting the disease in Liberia. He treated himself with an experimental drug, which was years from getting an approval from American health authorities, and he recovered.</p>	
<p>TC: 04.40.00 Soundbit 'Today is a miraculous day, I am thrilled to be alive'</p>	



TC: 04.46.10	
Offering experimental treatments is ethically questionable, since side-effects as well as possible positive effects are unknown.	
TC: 04.58.00	
In the case of Kent Bradley he is a doctor himself and can weigh the pros and cons. But in other cases, doctors might be motivated by a desire to be the first to document health effects of a new treatment and this could tempt them to pressure patients into agreeing to experimental treatment.	
TC: 05.20.00	
Transparency in public health policy can be difficult since public health authorities need to be able to work in peace during an outbreak, but on the other hand the public trust in authorities suffers, when the public feel misinformed or held in ignorance, as in the case of the swine flu.	
TC: 05.39.00	
TC: 05.41.00 Text	
What do you think? Enjoy the debate TC: 05.49.00	

4. TRUST, ACTION AND ACCESS TO KNOWLEDGE /MANUS

Speak	Translation
Titel:	
Trust, action and access to knowledge	



<p>TC: 00.08.10</p> <p>In the previous sessions we have talked about the dilemmas faced by public health authorities in choosing what, how and when to communicate risks. In this session we would like to know more about which sources of information you trust, and why.</p>	
<p>TC: 00.26.14</p> <p>During pandemics and epidemics, public health authorities face a number of challenges.</p>	
<p>TC: 00.33.21</p> <p>When people are stressed or concerned, they are less likely to accept the validity of communication coming from authorities.</p>	
<p>TC: 00.43.09</p> <p>People often trust international organisations over national health authorities.</p>	
<p>TC: 00.50.16</p> <p>National authorities are seen as political organizations following their own interests more than organisations acting in the interest of the general public.</p>	
<p>TC 01.02.00</p> <p>When people don't trust an organisation, they are less likely to follow the recommendations of that organisation.</p>	
<p>TC: 01.11.20</p> <p>People might use different information channels</p>	



for getting information, like: the internet, social media, websites of organisations or leaflets.	
<p>TC: 01.23.21</p> <p>For example, during H1N1 swine flu pandemic, public authorities had to face rumours in the media and on the Internet talking about a conspiracy between them and pharmaceutical industries. When people use other ways of getting their information than the official websites rumours can be hard to handle.</p>	
<p>TC: 01.46.07</p> <p>Coping with the internet is a fundamental challenge for pandemic risk communication. Many public health authorities have been slow in the process of using the internet and social media.</p>	
<p>TC: 01.59.07</p> <p>Even if individuals say that they do not find internet-gathered information important, information acquired on the Internet can still influence people's behaviour.</p>	
<p>TC: 02.11.13</p> <p>Public health authorities could become better at incorporating social media in risk communication during pandemics and other health emergencies; It could lead to better communication - particularly if the authorities would engage in a dialogue with the public.</p>	
<p>TC: 02.31.00</p> <p>Public Health authorities, experts and groups in the public might disagree on what constitutes a</p>	



<p>risk, what information to share and how to understand it.</p> <p>How to deal with uncertainty is a tricky challenge for authorities.</p>	
<p>TC: 02.49.01</p> <p>In the early phase of pandemics or epidemics there is a lot of uncertainty. Communication about uncertainties can lead to an even greater loss of trust, but it might also increase people's trust in authorities, as they could become seen as more honest.</p>	
<p>TC: 03.08.03</p> <p>Risks related to pandemics are complex, and can be hard to understand and communicate. During pandemics, the quantification of risk is uncertain and subject to updates as long as data accumulates. Therefore it is hard to say exactly what the risk is.</p>	
<p>TC: 03.28.22</p> <p>The important questions the authorities are facing in risk communication are:</p> <p>How to be seen as trustworthy? How to use the internet and social media? And how to deal with uncertainty?</p>	
<p>TC: 03.47.00 Text</p> <p>What do you think?</p> <p>Enjoy the debate</p> <p>TC: 03.54.00</p>	



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share and move to face nasty bugs